

RAND

*Policy Evaluation of the Effects of the 1996  
Welfare Reform Legislation on SSI Benefits  
for Disabled Children: First Round Case  
Study Findings*

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## **PREFACE**

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (Title II (Subtitle B) of P.L. 104-193) changed the definition of disability used to determine eligibility for disabled children under the Supplemental Security Income (SSI) program. The law required the redetermination of eligibility status for children potentially affected by the new definition of disability.

This report is part of an evaluation being conducted by RAND for the Social Security Administration (SSA) titled “Policy Evaluation of the Effect of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children.” The study will evaluate how the 1996 welfare reform legislation affects SSI caseloads and costs, and how the law affects children and their families. The study includes analyses of SSA administrative data, nationally representative secondary databases, and case study interviews in four states. Additional information about the RAND evaluation can be found in Jeannette Rogowski, et al., *Background and Study Design Report for Policy Evaluation of the Effect of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children*, DRU-1808, Santa Monica, California: RAND, April 1998.

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## SUMMARY

The case studies in this policy evaluation were conducted to understand the impact of changes to the Supplemental Security Income (SSI) childhood disability criteria resulting from the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (P.L. 104-193) (Title II (Subtitle B)). This legislation provides a new, more restrictive definition of disability for children and has changed the disability determination process for children in addition to causing a significant number of children to lose SSI income. The Social Security Administration (SSA) Office of Research, Evaluation, and Statistics evaluation focuses on the effects of this law on former recipients and on local service environments.

These case studies provide qualitative information on the policy change, based on the perceptions and experiences as reported by those who were interviewed. The primary objective of the case studies is to generate hypotheses and to interpret findings from the quantitative analyses in the policy evaluation. To serve this objective, we undertook procedures in site selection and sampling so that we could create the richest and most diverse set of perceptions and experiences possible, within the constraints of the study design and scope. Taken together, these reported perceptions and experiences are useful for creating research questions that the quantitative analyses can potentially address. The case studies also provide a useful context for interpreting the quantitative findings. Thus a second objective is to describe a possible range of policy effects, as reported by a small number of affected families, and as described by agencies and providers who serve children with disabilities. The case study approach does not permit generalization about policy effects for all families and communities, however. The detailed qualitative information adds to our understanding of the policy's impact but should not be used to make general statements about families' experiences overall. Instead, the summary findings that are described throughout the report are intended to describe areas of possible impact from which hypotheses can be generated. While some of the case study findings are phrased as or may appear to be conclusions, these findings are not intended to be conclusions about the experiences of families and providers in the sites we visited, or about the experiences of those in other communities.

To achieve the objectives of generating hypotheses based on a range of perceptions and experiences, the policy evaluation includes two rounds of case studies in five locations across the nation, specifically Los Angeles and Fresno, California; Detroit, Michigan; Hartford, Connecticut; and New Orleans, Louisiana. In the first round of case study site visits, we interviewed SSA staff; representatives of state/local agencies (such as Medicaid, mental health, and public health); direct providers of health, mental health, and education services; legal advocates; and 44 families with children who were affected by the welfare reform child SSI eligibility change.

This first round of case studies, conducted from August to October 1998, focused on the eligibility redeterminations, the initial impact of PRWORA changes to SSI on

children and families, and the initial responses of families to redetermination and to the loss (or potential loss) of SSI income. Follow-up interviews will be conducted approximately one year later in 1999 with many of the same individuals.

The major findings from the first round of case studies are delineated below, first for the SSA offices and other agencies, and then for affected children and families. These findings are based on experiences with the policy change as reported to us by families and other key informants whom we interviewed. It is important to keep in mind that these findings are based upon a relatively small number of interviews, which were conducted in five sites chosen purposefully from different geographic locations. Thus, the distribution of outcomes does not necessarily reflect what would be observed for a larger, statistically representative sample of the affected agencies and populations in the communities visited, or what would be observed for the country as a whole. As other components of the evaluation are completed, they can be integrated with these findings and those from the second round of case study interviews to provide a more complete portrait of the impact of the policy changes.

### **Impact on SSA Offices**

*SSA offices were faced with overwhelming and complex workloads.*

Agency respondents consistently reported that the childhood disability changes created overwhelming workloads for federal SSA offices as well as State disability determination agencies. The incremental adjustments during the policy's implementation and the monitoring procedures developed over time created a highly complex set of policies and procedures that were reported to be difficult for staff to implement with complete accuracy and speed.

*The dedicated accounts policy is increasing the childhood workload in SSA field offices.*

Although separate from the SSI childhood disability eligibility changes, the dedicated accounts policy—which restricts the way that families can access and spend lump sum payments—was reported to be an emerging, significant implementation issue in the SSA field offices that we visited. The dedicated accounts established for some children whose cessations were overturned on appeal (resulting in lump sum payments) were reported by staff to be time-consuming because of the need for individual judgment and for monitoring, and because new roles are defined for staff. Some office staff felt that this issue may become more important as more affected families receive lump sum payments.

## **Impact on Medicaid and Other Agencies**

*Few Medicaid agencies have finalized their procedures for implementing the “grandfathering” provision of the 1997 Balanced Budget Act.*

Medicaid agencies in the case study states with SSI-linked Medicaid eligibility had not yet fully implemented their responses to the Balanced Budget Act of 1997 provisions for “grandfathering” Medicaid eligibility for some affected children. All states had received lists of affected children from SSA. Our interviews with Medicaid agency staff revealed that as of mid-1998, it was not yet clear in these states exactly how pre-PRWORA SSI criteria information would be gathered for this “grandfathered” group, or what information the state might require in future eligibility determinations. Administrators from most of these states expected that children who lose SSI-linked Medicaid would still qualify for Medicaid in a low-income or cash assistance aid category, or else would qualify for the new federal Title XXI State Child Health Insurance Program (SCHIP) in the state.

*The impact of the childhood eligibility change has been less than expected for most agencies and providers*

A number of interviewed agency administrators and providers had expected to have a more substantial role in responding to the policy changes and to observe a larger impact on their populations than they have observed so far. Legal assistance programs planned and assembled resources in response to the eligibility changes, but those we interviewed had not yet seen a large number of requests for assistance from families.

## **Impact on Children and Families**

*Most parents understood the SSI changes in welfare reform but were confused by the redetermination procedures.*

Most families that we interviewed stated that they understood the initial SSA letters they received, which described the 1996 welfare reform changes regarding SSI, the purpose of the redeterminations that were underway, and options that a family had to appeal. Most parents recalled receiving an initial letter describing welfare reform and also recalled receiving a “good news” letter (sent by SSA in Spring 1998) explaining that they had a second opportunity to appeal, if they had not already done so. The specific features of the process that families reported to be confusing were how the appeals process worked, what their benefit continuation options were, and what the implications of requesting benefit continuation were in terms of possible payback requirements.

*Some children in every site became disenrolled or lost Medicaid eligibility during redetermination and/or during the appeals process.*

Parents of several children in each site that we visited reported that their child had lost Medicaid eligibility or had become disenrolled for some period during the redetermination and/or appeals process. This was reported by some of the interviewed families even in the states that had not yet put specific Medicaid eligibility redetermination criteria in place (and thus might not be expected to have enrollment losses), and in states with generous Medicaid income eligibility criteria for children. Given complex Medicaid eligibility rules, the specific reason for Medicaid loss was not always possible to identify in the family interviews. Many of the families we interviewed appeared to be unaware of their child's potential Medicaid eligibility under other non-SSI-linked Medicaid eligibility categories.

*Some families felt that the changes to the child's Medicaid eligibility and/or loss of the SSI income had impaired their ability to obtain needed services for their child.*

Some families reported that they were required to switch the affected child from fee-for-service Medicaid to a prepaid health plan (PHP) arrangement. Other parents were concerned that if the child ultimately lost SSI benefits, they would have to switch the child from fee-for-service, and this might adversely affect their child's access to health care. In several of the families, the parent(s) had enrolled their child in private health insurance after Medicaid eligibility was lost, and this restricted the child's access to health care services relative to the benefits that had been available to the child through Medicaid. Access to mental health providers of choice and access to medications, were the major concerns identified by parents.

*Many families identified access to mental health or health services as more important than restoring lost SSI income.*

The families we interviewed frequently stated that access to medical and mental health services was more important to them than restoring or replacing SSI income. Several parents, including foster parents (all relatives), expressed specific needs for respite care and tutoring assistance for their special needs child so that the parents could manage the stress imposed on the family by the child's needs.

*Total household income declined in most families who lost SSI income.*

Many of the parents we interviewed stated that the loss of SSI benefits caused them to enter the workforce or to increase their working hours. Some families stated that they had temporarily increased their total household income by applying for Food Stamps at the same time that they requested SSI benefit continuation during an appeal. Other parents reported that household income had declined even further after losing the child's SSI benefits, because they quit their jobs or reduced their working hours to meet increased demands on their time by their children due to behavior problems in school or other demands.

*Many families turned to public assistance to replace lost SSI income.*

Of the families we interviewed who turned to public assistance to compensate for losing SSI income, most reported turning to welfare and Food Stamps programs. About 25 percent of the 44 families had successfully applied for welfare and/or Food Stamps. Several parents were trying to obtain child support payments from absent fathers, in response to losing (or anticipating the loss of) SSI benefits for their child.



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## ACRONYMS

<b>Acronym</b>	<b>Definition</b>
ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AFDC	Aid to Families with Dependent Children
ALJ	Administrative Law Judge
ASPE	Assistant Secretary for Planning and Evaluation (DHHS)
BBA	Balanced Budget Act of 1997
CCS	California Children Services
CFR	Code of Federal Regulations
CDR	continuing disability review
CE	consultative exam
CR	claims representative
CSHS	Children's Special Health Services (Louisiana)
DA&A	Drug addiction and alcoholism
DCF	Department of Children's Services (Connecticut)
DCFS	Department of Children and Family Services (California)
DDS	Disability Determination Service
DED	Disability Evaluation Division, Department of Social Services (California)
DHHS	Department of Health and Human Services
DHO	Disability Hearing Officer
DHU	Disability Hearing Unit
DMH	Department of Mental Health (California)
DPSS	Department of Public Social Services
DQB	Disability Quality Branch
FBR	federal benefit rate
FIA	Family Independence Agency (Michigan)
FITAP	Family Independence Temporary Assistance Program (Louisiana)
FO	Field Office (SSA)
FPL	federal poverty line
FTE	full-time equivalent
GA	General Assistance
GAO	General Accounting Office
HCFA	Health Care Financing Administration
HOTS	Hearing Officers Temporary Staff
IEP	Individualized Education Plan
IFA	individualized functional assessment
IVT	Interactive Video Training
LAUSD	Los Angeles Unified School District
LBW	low birth weight

MDW	Manual Development Worksheet
MIS	management information systems
MOU	memorandum of understanding
MPAS	Michigan Protection and Advocacy Services
MR	mental retardation
MSIS	Medicaid Statistical Information System
NCYL	National Center for Youth Law
OFS	Office of Family Support (Louisiana)
OHA	Office of Hearings and Appeals
PHP	prepaid health plan
PL	Public Law
PRWORA	Personal Responsibility and Work Opportunity Reconciliation Act of 1996
SCHIP	State Child Health Insurance Program
SED	severe emotional disturbance
SIPP	Survey of Income and Program Participation
SR	service representative
SSA	Social Security Administration
SSI	Supplemental Security Income
TANF	Temporary Assistance to Needy Families

## **1. INTRODUCTION**

### **1.1 OVERVIEW OF THE 1996 CHANGES TO CHILDHOOD SSI ELIGIBILITY AND RELATED POLICY CHANGES**

The Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA, or PL 104-193), signed into law by President Clinton on August 22, 1996, changed the determination of childhood disability by providing a new statutory definition of disability for children applying for Supplemental Security Income (SSI). As a result of PRWORA, of the approximately one million children receiving childhood disability-related SSI, 264,000 were sent informational notices in November and December of 1996 informing them that they were subject to eligibility redetermination. Under the law, children who were found not to meet the new disability criteria were subject to losing their SSI benefits starting in July 1997.

The PRWORA both changed the criteria used to determine childhood disability and established redeterminations of disability for certain groups of children up to and including age 18. Under the law, the comparable severity criteria was replaced with a definition of disability unique to children: “a medically determinable physical or mental impairment, which results in marked and severe functional limitations” (SSA, 1997). Determination of eligibility for children was revised to reflect this new definition of childhood disability, with an emphasis on assessing the severity of impairment. The legislation eliminated the individual functional assessment (IFA). Pursuant to PRWORA, SSA created a three-step evaluation process of the functional equivalency of an impairment to a condition noted in the Listing of Impairments (in Appendix 1 of Subpart P of 20 CFR Part 404, called “the Listing”). Functional equivalency under the new SSI eligibility standards requires at least two marked limitations for a child. In addition, the Listing for childhood mental disorders (112.00C2 and 112.02B2c) was modified to remove references to maladaptive behavior from the personal/behavioral domain.

PRWORA provisions affected two additional groups of potential child beneficiaries. Pursuant to PRWORA and the regulations that followed, individuals who are 18 years of age and older are considered to be adults, not children. The PRWORA requires that when child SSI beneficiaries reach 18 years of age, their eligibility must be redetermined using the adult disability criteria. Continuing disability reviews are required not less than once every three years for children under age 18 who have impairments that are considered likely to improve, and within the first year for infants whose low birth weight contributed to their SSI eligibility.

Policy implementation procedures are described in greater detail in Appendix A. A very brief overview of the redetermination steps includes the following. Notices were sent to families of affected children to explain welfare reform provisions. Children whose eligibility was not subject to the redeterminations were screened from the redetermination caseload, and notices were sent to the remaining children to notify families that their

child's eligibility would be redetermined and that they had specific options for appeal, as well as opportunities for legal assistance (with hotline numbers for legal aid included in the notices). SSA worked with the American Bar Association (ABA) after welfare reform was passed to establish legal support for families whose children were affected.

Cases ceased after the initial review could be appealed within 60 days and benefit payment continuation could be requested by the family within 10 days of the notice of cessation. Appealed cases are reviewed at a reconsideration level with a case file review and face-to-face hearing before a Disability Hearing Officer (DHO). Subsequent levels of appeal (based on cessation at the previous level) include hearings before an Administrative Law Judge (ALJ), then appeal to the Appeals Council, and finally a filing of a civil action in federal court. (Redetermined cases also could be ceased due to non-disability reasons such as financial ineligibility.) For welfare reform provisions regarding children at age 18, continuing disability reviews (CDRs) were undertaken with similar notification and appeal opportunities for families.

The 1997 Balanced Budget Act (BBA) was passed in August 1997, one year after the passage of the PRWORA. One of the most significant provisions in the 1997 Balanced Budget Act related to child SSI beneficiaries was the "grandfathering" of Medicaid eligibility for children who lost their SSI benefits following eligibility redetermination pursuant to PRWORA requirements. Prior to the 1997 BBA, children who lost their SSI benefits would no longer be automatically eligible for Medicaid benefits based on SSI eligibility (in most states, SSI eligibility automatically confers Medicaid eligibility). The 1997 BBA continued Medicaid eligibility for children who were receiving SSI on August 22, 1996 and who effective July 1, 1997 (or later) lose SSI payments because of a disability determination under the rules enacted by the 1996 PRWORA.<sup>1</sup>

Pursuant to the 1997 BBA, SSA has provided the States (at least three times) with lists of children whose SSI benefits were ceased due to welfare reform redeterminations. These lists were made available so that States can evaluate the children's Medicaid eligibility based on BBA provisions, or under other Medicaid eligibility aid categories if BBA protections do not apply, due to income changes for example.<sup>2</sup> (The regular

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<sup>1</sup>Children living in States that do not provide Medicaid eligibility to children based on disability, or in States that use the more restrictive disability definition permitted by Section 1902(f) of the Social Security Act, are not affected by this provision; also, a child who loses SSI after August 22, 1996 for a non-disability reason does not have protected Medicaid eligibility under this provision (HCFA, November 13, 1997). Following the 1997 BBA, HCFA began working with SSA to determine whether SSA medical evidence could be made available to States to facilitate determination of whether a child covered by the provision meets disability requirements in effect prior to August 22, 1996 (HCFA, November 13, 1997).

<sup>2</sup>HCFA also has issued guidance to States on their responsibilities in implementing BBA "grandfathering" provisions and on the use of SSA lists made available for this purpose (HCFA, October 2, 1997).

monthly updates on entering and exiting SSI beneficiaries continue to be provided by SSA directly to State Medicaid agencies, through the State Data Exchange (SDX) system.)

Another relevant provision of Section 2101 of the 1997 BBA was the new (Social Security Act) Title XXI State Children's Health Insurance Program (SCHIP). SCHIP provides federal funding to States to expand Medicaid eligibility for low income children and to create separate (non-Medicaid) child health insurance programs for low-income children ineligible for Medicaid. (Further detail on BBA changes to childhood disability determination is provided in Appendix A.)

In the Fall of 1997, Commissioner Apfel initiated a "Top-to-Bottom" review of the implementation of the childhood disability redetermination process. The results of that review were made available in the Commissioner's Report that was released in December 1997 (SSA, December 17, 1997). This review identified four additional changes in the redetermination process that SSA would undertake. First, the appeals and benefit continuation process was reopened, with a new 60-day appeals period (and a new 10-day period to request benefit continuation) for cases where benefits had been ceased and no appeal had been filed. Families who had appealed without requesting benefit continuation were given a new 10-day period in which to request that benefit payments continue during the appeal. Families who had not appealed a cessation or who had appealed but had not requested benefit continuation during appeal were notified of their opportunity through the Reappeals and Benefit Continuation letter frequently referred to as the "good news" letter, which contained simplified language in English and in Spanish. This provided another opportunity to families who may not have understood their appeal and benefit continuation options.

Second, SSA undertook a review of all cases ceased after redetermination that involved coding for a primary diagnosis of mental retardation (MR). SSA also reviewed initial denials that occurred after August 22, 1996 that showed coding for mental retardation. This was due to concerns that some redetermination cessations in mental retardation cases might be wrong, although coding for mental retardation was known to appear in cases without mental retardation diagnosis due to the lack of specific codes prior to welfare reform. Third, all cessations based on a "failure to cooperate" were also to be reviewed to ensure that the cooperation of beneficiary families was fully sought and documented. Finally, SSA undertook a further quality review process, examining cases in each Disability Determination Service (DDS) office with a high likelihood of error based on quality assurance data. (Appendix A provides additional detail regarding the actions that followed the Commissioner's report.)

Overall, SSA estimates that as a result of the actions directed by the Commissioner, 100,000 of the approximately 264,000 children subject to redetermination will lose their benefits after all appeals have been completed. This is revised downwards from the initial estimate of 135,000 children who would lose benefits as a result of the 1996 PRWORA legislation.

## 1.2 OBJECTIVES AND APPROACH OF THE CASE STUDIES

SSA is interested in assessing the effects of PRWORA on children who have lost or may lose SSI disability benefits. The case study component of the “Policy Evaluation of the Effect of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children” was designed to provide information on the progress of the redetermination process and to evaluate its effects on affected children and their families. The case study methodology is useful for identifying a range of experiences and responses of families, SSA offices, and agencies and providers across the participating sites pursuant to PRWORA, although the case studies are not designed (or adequate in size) to produce nationally representative information on policy impact, or conclusions about the overall impact in the visited states and localities. An important objective of the case study component is to generate hypotheses that can be tested in the quantitative analyses of this evaluation and used to interpret the results of the quantitative analyses. These goals will be addressed through two rounds of case study interviews, approximately one year apart. The primary focus of the first round of case studies, covered in this report, is to describe some of the perceptions and experiences within the sites we visited, with respect to the impact of the legislation on the cohort of children whose eligibility is being redetermined using the revised disability criteria.

The first round case studies focused on the following domains that address the impact of the policy change on children and families:

- **Impact of the policy implementation.** How well did families understand their options during eligibility redetermination, including rights to appeal, benefit continuation, and access to legal assistance?
- **Access to medical care.** What happens to children’s Medicaid eligibility, Medicaid enrollment, and access to health care change for children who lose SSI benefits?
- **Impact of health care arrangements.** Do changes in SSI eligibility affect children’s enrollment in fee-for-service vs. prepaid financing arrangements for children whose Medicaid eligibility continues, and does enrollment in prepaid arrangements affect children’s access to care?
- **Effects on family income.** What happens to family income and use of public assistance programs after children’s SSI benefits are terminated? What changes occur in the employment status and earnings of the children’s primary caregiver(s)?
- **Effects on living arrangements.** How does the loss of SSI eligibility affect the living arrangements of children and their families, including household moves and entry into foster care?

In addition, the case studies considered the following effects of the policy change on SSA offices and other agencies and providers:

- **Effects on SSA offices.** How have SSA offices been affected by the policy changes, and what have been the major challenges to implementing the changes?
- **Effects on other agencies/providers.** How have providers and public agencies responded to, and been affected by, the changes to childhood SSI eligibility?
- **Impact of social services reform.** How does the organization and financing of local public services affect availability of public assistance, health care, and mental health services for children and families who are affected by the eligibility changes?

The two rounds of case study interviews are being conducted in five sites: Los Angeles and Fresno, California; Detroit, Michigan; Hartford, Connecticut; and New Orleans, Louisiana. In this report, we present our findings for the first round of interviews conducted between August and October of 1998. Across the five sites, we interviewed a total of 44 families who were affected by the 1996 changes to SSI childhood eligibility. We also visited several SSA offices and state agencies in each of these sites. Interviews with regional and field SSA offices provided information on administration of the redetermination and appeals processes for childhood SSI beneficiaries. Interviews with agencies other than SSA provided a broad perspective on the impact of the SSI childhood eligibility changes for the local community. State, local, and private agencies and providers who were interviewed included organizations such as the state Medicaid agency, social service agencies that administer public assistance and family work programs, child protective services agencies, advocacy organizations, and other organizations that provide services to children with disabilities.

The findings from the first round of case studies are useful for understanding the types of experiences that families have had so far in the redetermination process, the different ways and patterns in which families are responding to the eligibility changes, and the ways that children are being affected. The findings also provide insight into the major implementation issues and challenges for SSA offices and for other public agencies that serve children with disabilities.

The five sites were selected to provide variation in the implementation and impact of the policy changes. While the case studies provide a detailed picture of the legislative impact, the findings should be interpreted with some caution. Although there is significant variation in health and social service systems and geographical diversity across the selected sites, generalizability of findings to the experiences of other national locales is limited by the small number of sites and families.

### **1.3 ORGANIZATION OF THE REPORT**

The remainder of this report is organized as follows. Section 2 describes the methodology used to design and implement the case studies. Sections 3 through 7 provide detailed site visit reports for each of the five sites, with results from agency interviews (SSA offices and Medicaid agencies, and several other public or private agencies) and family interviews. The sites are presented in the following order: Los Angeles, Fresno,



Hartford, New Orleans, and Detroit. The final section provides a synthesis of our findings. An Appendix provides additional detail about the redetermination process that resulted from the 1996 welfare reform and the subsequent policy changes in the 1997 BBA and the Commissioner's Top-to-Bottom review.

## **2. CASE STUDY METHODOLOGY**

In this section, we detail the methodology of the case study component of the evaluation of the impact of the 1996 welfare reform legislation on disabled children receiving SSI. In particular, we discuss the rationale for the selection of the five sites we visited and we provide a description of the policy environment for the selected sites. We then discuss the protocols for conducting interviews with SSA offices and other government agencies and providers, and for conducting interviews with families of affected children. We also discuss the limitations of the case study methodology.

### **2.1 SELECTION AND CHARACTERISTICS OF CASE STUDY STATES**

#### **2.1.1 Rationale for Site Selection**

The policy evaluation called for case study visits in four states. Given the limited number of sites to be visited, the selection of states was not intended to provide a statistically representative sample. Rather, we selected states that differed across important dimensions, such as caseload characteristics and policy environment, to maximize the amount of variation that would be observed across the case study sites. The purpose of this strategy was to provide a diverse portrait of the perceptions and experiences of families and service providers in several different sites across the U.S.

We considered the following eight criteria for selecting the state sites for the case studies:<sup>3</sup>

- 1) SSA administrative region;
- 2) Absolute size of the SSI caseload;
- 3) Participation rate in SSI;
- 4) Frequency of IFA and maladaptive behavior cases within the SSI caseload;
- 5) Continuation rates from the initial redeterminations;
- 6) Existence and generosity of state supplementation of SSI benefits;
- 7) Existence and nature of state Medicaid waivers for managed care; and
- 8) Coverage of state in non-SSA databases to be used in quantitative analysis.

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<sup>3</sup>There are clearly other indicators that could have been added to the list, although with only four case study sites to be selected, there is a limited number of variation that can be achieved. Nevertheless, we believe the criteria delineated here represent the most salient dimensions along which states vary and hence the outcomes for affected families.

By selecting states in different SSA administrative regions, we were likely to pick up variation in SSA policies with respect to program administration and implementation of the new disability determination criteria. The set of criteria listed above also led to variation in the overall size, participation rate, and composition of the SSI caseload. These parameters may have implications for the ability of SSA staff and the adjudication process to handle the transition to the new rules, as well as for the ability of local social service providers to make up for the loss of SSI benefits among the affected families. Finally, the implications of losing SSI benefits are likely to vary depending on the generosity of the state's SSI cash assistance levels, the way in which Medicaid services are provided to both SSI and non-SSI program participants, and the availability of social services to non-SSI enrollees.

Based on these criteria, we selected the following four states: California, Connecticut, Louisiana, and Michigan. Each state represents a different SSA administrative region (San Francisco, Boston, Dallas, and Chicago, respectively) and thus should capture variation attributable to the regional SSA administrative structure. These four states also capture much of the important variation that is likely to affect the direction and magnitude of the impact of the 1996 welfare reform legislation on families and service providers. To illustrate this variation, we provide additional detail regarding the four case study states in terms of the variation across the first seven characteristics listed above which are most relevant for interpreting the findings of the case study interviews.<sup>4</sup>

### **2.1.2 Caseload Characteristics in Selected Case Study States**

As shown in Table 2.1, the absolute SSI childhood caseload size, as of December 1996, varied significantly across the selected case study states, ranging from one of the highest state caseloads (California) to one of the lowest caseloads (Connecticut). There were sharp differences as well in underlying SSI participation rates, ranging from 0.7 percent of the childhood population in Connecticut to 3.1 percent of children in Louisiana. These differences reflect, in part, underlying differences in child poverty rates across the four states which ranged in 1995 from a low of 13.6 percent in Connecticut to a high of 31.3 percent in Louisiana.

The proportion of the SSI caseload with eligibility related to IFA or maladaptive behavior—the groups most affected by the new eligibility criteria—also varied considerably across the four states. California (14 percent) and Michigan (31 percent) represented two extremes in IFA caseload shares, compared to 23 percent nationally.

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<sup>4</sup>The last criteria we listed above is the inclusion of the selected states in the non-SSA databases that will be used in the quantitative analysis of the policy evaluation. As described in Rogowski, et al. (1998), we will analyze the impact of the 1996 welfare reform legislation on children and families using two nationally representative databases: the Survey of Income and Program Participation (SIPP) and the Medicaid Statistical Information System (MSIS). Since the SIPP is a nationally representative database, all case study states are included in it. Two of the case study states (California and Michigan) report data to the MSIS.

Connecticut (1 percent) and California (6 percent) span much of the variation in maladaptive behavior rates, compared to 4 percent nationally. This variation may reflect differences in the underlying incidence and identification of disabling conditions among the population of children in each state, as well as differences in the practices and incentives of the states with respect to SSI enrollment (Perrin and Stein, 1991).

**Table 2.1**  
**SSI Caseload Characteristics and National Rankings**  
**for the Selected Case Study States**

Case Study State	SSA Region	Estimates of Children on SSI Based on						
		Children Age 0-17 (7/96)	Children on SSI (12/96)		IFA (8/96)		Maladaptive Behavior (8/96)	
		No. (Rank)	No. (Rank)	% (Rank)	No. (Rank)	% (Rank)	No. (Rank)	% (Rank)
		[1]	[2]		[3]		[3]	
California	San Francisco	8,866,413 (1)	79,400 (2)	0.9 (38)	11,273 (7)	14.2 (44)	4,877 (2)	6.1 (8)
Connecticut	Boston	797,950 (29)	5,550 (35)	0.7 (47)	1,188 (34)	21.4 (26)	76 (45)	1.4 (47)
Louisiana	Dallas	1,233,455 (21)	38,590 (9)	3.1 (2)	10,485 (10)	27.2 (11)	998 (11)	2.6 (44)
Michigan	Chicago	2,537,014 (8)	41,880 (8)	1.7 (13)	12,803 (2)	30.6 (4)	1,996 (5)	4.8 (16)
U.S. Total		69,048,323	998,280	1.4	228,069	22.8	41,175	4.1

SOURCE: [1] U.S. Bureau of the Census, 1997; [2] SSA, December 1996; [3] Bazelon Center, 1997.

### 2.1.3 Redetermination Process in Selected Case Study States

The initial continuation rates differed substantially across the four states as well. As shown in Table 2.2, as of November 1997, Louisiana's initial continuation rate (23.1 percent) was approximately 40 percent of California's rate (59.3 percent). These two states represent the extremes of the range in initial continuation rates across states. The initial continuation rates for Connecticut (43.4 percent) and Michigan (51.3 percent) were intermediate. Differences also existed in the rate at which cases were continued after reconsideration, ranging from 73 percent in California to 100 percent in Michigan.

The case study states also represent different experiences with the accuracy of cessations and continuations.<sup>5</sup> As reported in the Commissioner's Report, cessation accuracy rates ranged in the case study states from 89.7 percent in California to 99.2 percent in Louisiana. Across all states, the cessation accuracy rate ranged from 81.2 percent to 100 percent, and the national average was 93.4 percent. The case study states also varied with respect to the accuracy of continuations, from 85.4 percent in Michigan to 97.6 percent in Connecticut. The range of continuation accuracy across all states ranged from 100 percent to 80.7 percent (with one low outlier, Pennsylvania, at 69 percent). Nationally, the continuation accuracy rate was 91.5 percent.

**Table 2.2**  
**SSI Childhood Redetermination Progress and Payment Levels**  
**for the Selected Case Study States**

Case Study State	Initial and Reconsideration Levels of Childhood Redeterminations						Average Federal or State SSI Suppl. (3/97)	
	Accuracy Rate of Initial Redeterminations (12/97)		Cases Continued After Initial (11/97)	Cases Continued After Reconsideration (11/97)	Average Federal SSI Payment (3/97)			
	Cessation	Continuation	No.	%	No.	%		
	[1]	[1]	[2]		[2]			
California	89.7	92.5	7,575	59.3	427	73.0	387.08	161.86
Connecticut	98.2	97.6	513	43.4	53	79.1	389.19	262.74
Louisiana	99.2	86.1	2,590	23.1	159	92.4	394.39	69.28
Michigan	94.3	85.4	6,054	51.3	127	100.0	404.54	120.41
Total U.S.	93.4	91.5	94,191	39.8	5,999	57.1		

SOURCE: [1] SSA, December 17, 1997; [2] SSA, November 1997; [3] SSA, March 1997.

#### 2.1.4 Policy Environment in Selected Case Study States

Several characteristics of the policy environment varied considerably among the four states. All four states supplement the federal SSI payment, and as shown in Table 2.2, the average state supplement (whether federally or state administered) ranged from \$69 in Louisiana to \$263 in Connecticut. Such differences in the SSI payments suggest that the consequences for families of losing SSI income are likely to differ across these states.

<sup>5</sup>SSA's quality assurance rates for accuracy capture deficiencies in documentation ( i.e., in the evidence that formed the basis for the determination, which may not mean that the determination was incorrect) or incorrect continuation and cessation determinations. The regulatory threshold for accuracy is 90.6 percent (SSA, December 17, 1997).

Another key dimension considered in the selection of case study sites was policy characteristics of the state Medicaid programs. The features of a state's Medicaid program are relevant to children on SSI who receive health insurance coverage through Medicaid. One important feature of state Medicaid programs concerns waivers of federal Medicaid regulations; states that operate under such waivers are able to mandate enrollment of certain population groups into managed care arrangements. State managed care enrollment provisions for children with disabilities vary across the states. Table 2.3 provides information on key Medicaid managed care enrollment policies for children with disabilities or chronic medical diagnoses in the case study states.

**Table 2.3**  
**Medicaid Managed Care Enrollment Policies: Mandated, Voluntary, and Excluded Child Populations for the Selected Case Study States**

Case Study State	Inclusion of Children in Medicaid Managed Care		Child or Medical Service Exclusions from Managed Care
	Voluntary Enrollment Groups	Mandatory Enrollment Groups	
California	SSI (some counties) Foster care (some counties)	SSI (some counties) Title V (some counties) TANF	Services for Title V conditions (some counties)
Connecticut	None	TANF	Home and community based waiver services
Louisiana	None	SSI TANF	Eligibility as child in foster care
Michigan	Title V	SSI TANF	Eligibility as child in foster care

SOURCE: HCFA, 1996, 1997, 1998; National Governor's Association, 1996; GAO, 1995.

NOTES Columns indicate which child beneficiaries in each state may enroll (voluntary), must enroll (mandatory), or are exempted from or are entitled to service exclusions from Medicaid managed care.

The Medicaid managed care provisions may include exemptions for the SSI population and/or more specifically, for children with behavioral or mental disorders. In two of the case study states, Louisiana and Michigan, children with SSI-linked Medicaid eligibility are not generally exempted from mandatory managed care enrollment. In most California counties, enrollment in managed care arrangements is voluntary for children with SSI-linked Medicaid eligibility. In addition, in California and Michigan, Medicaid waivers provide for inclusion of children with mental health conditions in managed care plans, which has particular relevance for childhood SSI recipients with mental disorders.

### **2.1.5 Other Aspects of Policy Environment in Selected Case Study States**

Finally, although we did not specify additional criteria in selecting these four states, there are other important dimensions along which these sites vary, including the economic environment, the generosity of other social support programs (e.g., health insurance,

Temporary Assistance to Needy Families (TANF), state General Assistance (GA)), and the support available to families through the public sector (e.g., special education resources or the extent of integration of the health care system for children). Below we discuss two of the most salient policy areas for assessing the impact of the SSI policy changes: the State Child Health Insurance Program (SCHIP) and the TANF welfare reform provisions.

***Title XXI State Child Health Insurance Program (SCHIP) Provisions Across Case Study States***

Although the Title XXI State Child Health Insurance Program (SCHIP) expansions of health insurance to children were still under development when case study sites were selected, the case study sites varied significantly in terms of the SCHIP options that have been adopted. State expansions as of October 1998 are illustrated in Table 2.4. Three of the five states expanded Medicaid eligibility and also created a separate program for low-income children. Connecticut expanded coverage most significantly with Medicaid eligibility expanding to 300 percent federal poverty line (FPL) through age 18 years and with a premium buy-in provision for families above 300 percent FPL.

**Table 2.4**  
**Medicaid Expansion and Implementation of the State Children's Health Insurance Program (SCHIP) for the Selected Case Study States**

Case Study State	Pre-BBA Medicaid Child Eligibility Levels <sup>a</sup>			Eligibility Expansions <sup>a</sup>			Start Dates		Benefits (for state plan)
	Under 6 yrs	6-15 yrs	15+ yrs (AFDC 7/16/96)	Medicaid (FPL)	State program (FPL)	Medicaid	State Program	Cost-sharing <sup>a</sup>	
California	133%	100%	82%	14-18 yrs to 100%	0-1 yrs 200-250% 1-6 yrs 133-200% 7-18 yrs 100-200%	3/98	5/98	Yes >100%	State employee + vision + dental
Connecticut	185%	185%	185% to 16	0-18 yrs to 185%	0-18 yrs to 300% >300% premium buy-in	1/98	4/98	Yes >185%	State employee package
Louisiana	133%	100%	100% to 18	0-18 yrs to 133%	None	11/98	n/a	No	n/a
Michigan	150%	150%	150% to 16	16-18 yrs to 150%	0-18 yrs to 200%	5/98	5/98	Yes >150%	State employee package

SOURCE: National Governors' Association Center for Best Practices, 1998.

NOTES:

<sup>a</sup>Figures for eligibility thresholds are relative to the federal poverty level (FPL).

### ***Welfare Reform Provisions Across Case Study States***

The provisions that the selected case study states adopted pursuant to the 1996 welfare reform changes to the Aid to Families with Dependent Children (AFDC) program also varied. Key elements of state welfare reform provisions are provided in Table 2.5.

Both Michigan and Connecticut are further along than other states in implementing key reforms and in imposing work requirements and time limits for public assistance beneficiaries with TANF effective dates in October 1996. Michigan and California have more liberal time limit provisions relative to Connecticut and Louisiana, which have time limits under 60 months. Most states have adopted federal work requirement standards of 20 hours per week for single parent households (26 hours per week in California) and 35 hours per week for two parent households.

**Table 2.5**  
**Elements of Welfare Reform Implementation for the Selected Case Study States**

Case Study State	TANF Effective Date	Continue Waivers	Time Limits < 60 mos	Work Requirement < 24 mos	Work Hours Same as Federal Law	Transition Child Care > 12 mos	Transition Medicaid > 12 mos	Diversion Payments
California	1/1/98	Yes	No <sup>a</sup>	Yes (immediate)	Yes <sup>d</sup>	Yes (24 mo)	Yes (24 mo)	Yes <sup>g</sup>
Connecticut	10/1/96	Yes	Yes <sup>b</sup>	Yes (21 mo)	Yes	Yes <sup>e</sup>	Yes (24 mo)	Yes <sup>h</sup>
Louisiana	1/1/97	No waiver	Yes <sup>c</sup>	Yes (immediate)	Yes	No	No	No
Michigan	10/1/96	Some	No	Yes (immediate)	Yes	No	No <sup>f</sup>	No

SOURCE: National Governors' Association Center for Best Practices, 1998.

**NOTES:**

- <sup>a</sup> Applicants may receive assistance for 18 consecutive months and current recipients may receive benefits for 24 consecutive months, within a 60 month lifetime limit.
- <sup>b</sup> Time limits are 21 months with provisions permitting 6 month extensions.
- <sup>c</sup> Current recipients may receive benefits for 24 consecutive months within a 60 month lifetime limit.
- <sup>d</sup> Work requirement for single parent families is 26 hours per week vs. 20 hours per week in federal law.
- <sup>e</sup> Transitional child care assistance will be provided if income does not exceed 75 percent of median family income.
- <sup>f</sup> Once transitional Medicaid ends, the state can use 100 percent of state funds to "buy-in" to Medicaid coverage for individuals whose employers do not provide coverage.
- <sup>g</sup> Counties determine the levels of diversion payments permitted.
- <sup>h</sup> Payments of up to 3 months of benefits are permitted.

Connecticut and California have longer transition coverage provisions for child care and for Medicaid coverage, both extending past 12 months. All case study sites but



Connecticut guarantee child care for TANF recipients. Transition child care following cessation of TANF benefits is provided to families in California and Connecticut, but not in Louisiana and Michigan. States may provide diversion assistance in the form of child care, health care, and other services or in the form of lump-sum payments in lieu of welfare assistance. California (where counties can set the payment levels) and Connecticut permit diversion assistance, while Louisiana and Michigan do not.

## **2.2 SELECTION AND CHARACTERISTICS OF LOCAL SITES WITHIN CASE STUDY STATES**

Within the four selected case study states, we selected one local study site (county) in each state except California where we selected two sites. Two sites were selected in California to allow us to capture variation both between and within the selected case study states. We chose to have two case study sites in California because of the state's geographic diversity and because there is variation in the social services system within the state; many social service programs in California are administered by county government (e.g., GA, Medicaid, child protective services).

Several of the selection criteria used for selecting case study states were relevant for choosing local study sites within each state, including:

- 1) Overall SSI childhood caseload and participation rate in the program for children under 18;
- 2) Absolute size and rate of IFA and maladaptive diagnoses in the redetermination caseload;
- 3) Caseload subject to redetermination and the size of the affected caseload relative to the total SSI childhood caseload;<sup>6</sup> and
- 4) Absolute number and rate of cases terminated and not under appeal as of January 31, 1998.

In addition, we examined the characteristics of counties in terms of an urban-rural continuum (to differentiate counties with major urban areas from those with smaller urban centers or more rural makeup). These measures were constructed from a combination of data from the Census Bureau (population estimates and urban/rural indicator); SSA published data (SSI caseload); and tabulations from the SSA Universe file (current as of January 31, 1998).

We ranked counties on the basis of these indicators to determine which counties were most affected by the 1996 welfare reform legislation, either in terms of absolute caseloads, or the share of the affected caseload. Additional considerations included the

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<sup>6</sup>The number of IFA plus maladaptive cases is less than the total number of cases subject to redetermination as some cases cannot be classified due to missing or "other" diagnoses codes.

need to establish a minimum caseload for purposes of selecting a subset of families to visit. Based on these indicators, a comparison of counties within the selected states indicated that no one county emerged in each state as having the largest absolute or relative caseload affected by the legislation according to all of the indicators. For example, the larger counties in Connecticut (Fairfield, Hartford and New Haven) all have similar characteristics, although Hartford County generally ranked first or second in terms of the absolute and relative size of the affected caseload.

Based on these criteria, the counties selected were Los Angeles and Fresno in California, Hartford in Connecticut, Orleans in Louisiana, and Wayne in Michigan. Table 2.6 describes the SSI caseload characteristics of the counties that were selected in each state. The selected sites all have large SSI caseloads and a large number of children terminated from SSI. For California, Los Angeles County was a natural choice as one of the two study sites. This county has a SSI caseload that is larger than the total caseload in many states (over 20,000 children at the end of 1995). Los Angeles County ranked first in several of our criteria, including the total numbers of IFA cases and maladaptive cases, and the total number of terminated cases in which there was no appeal pending. The other California site was selected to provide some important contrasts with Los Angeles County in terms of SSI program participation and county characteristics. Fresno County, which is a smaller urban county with a significant rural population in north-central California, ranked highest among California counties in the percent of children who are receiving SSI. Fresno also had high rankings in absolute case numbers as well as in the proportion of the SSI cases terminated and in the total number of cases terminated where there has been no appeal.

In the other case study states, one county was selected based on its rankings relative to other counties. In Connecticut, Hartford ranked highest on several of the criteria, including the percent of the child population on SSI, the total number of IFA and maladaptive cases, the number of cases to be redetermined, and the number of cases terminated with no appeal pending. In Michigan, Wayne County ranked highest on several of the criteria, including the total number of IFA and maladaptive cases, the number of cases subject to redetermination, and the number of terminated cases with no appeal pending. Wayne County (which includes the city of Detroit) also had high rankings in the percent of the child population on SSI. In Louisiana, Orleans had higher rankings on our criteria than any other county, with the largest percent of the child population receiving SSI, the largest number of IFA and maladaptive cases, the largest number of cases subject to redetermination, and the largest number of cases terminated with no appeal pending.

A comparison of the selected counties indicates significant variation, with the percent of the child population on SSI ranging from 0.95 percent in Los Angeles to 5.04 percent in Orleans, the proportion of child SSI cases that are IFA and maladaptive ranging from 14.6 percent (Los Angeles) to 25.1 percent (Wayne County), and the percent of redetermined cases terminated ranging from 39.4 percent in Los Angeles to 57.4 percent in Fresno. Thus the variation in these measures that was found across states also is captured in the variation across counties. We expect that this variation represents

differences in the service systems and/or populations, and that the differences across counties will provide for some variation in the experiences of agencies, providers, and beneficiaries across the study sites.

**Table 2.6**  
**SSI Caseload and Redeterminations in Selected Case Study Counties**  
**(from SSA Universe File as of January 31, 1998)**

Case Study State and County	Children on SSI (under 18) (rank in state)		IFA and Maladaptive Cases (rank in state)		Cases Subject to Redetermination (rank in state)		Cases Ceased, No Appeal Pending (rank in state)	
	No.	%	No.	%	No.	%	No.	%
California								
Los Angeles	24,767 (1)	0.95 (13)	3,611 (1)	14.6 (13)	5,535 (1)	22.4 (15)	1,071 (1)	19.4 (13)
Fresno	3,707 (6)	1.61 (1)	822 (3)	22.2 (1)	1,157 (3)	31.2 (2)	305 (2)	26.4 (5)
Connecticut								
Hartford	2,182 (1)	1.01 (1)	356 (1)	16.3 (4)	594 (1)	27.2 (4)	170 (1)	28.6 (3)
Louisiana								
Orleans	7,750 (1)	5.04 (1)	1,708 (1)	22.0 (32)	2,779 (1)	35.9 (29)	817 (1)	29.4 (35)
Michigan								
Wayne	14,605 (1)	2.30 (3)	3,666 (1)	25.1 (13)	5,521 (1)	37.8 (18)	1,171 (1)	21.2 (23)

SOURCE: Authors' calculations based on SSA Universe file as of January 31, 1998.

As discussed earlier, the selection of States and subsequently of counties was conducted to capture some of the potential variation in policy impact across different service systems and geographic areas and characteristics. Given the significant variability across the sites based on specific site selection criteria, the sites are likely to capture some of the differences in experiences and impact that may occur across communities nationally. However, the case study methodology and site selection was not designed to provide a nationally representative group of sites, and thus these findings are not necessarily generalizable to the experiences of other communities.

## **2.3 INTERVIEWING PROTOCOLS FOR SSA AND OTHER AGENCY STAFF**

### **2.3.1 Identifying, Contacting and Interviewing SSA Staff**

Interviews with SSA office staff began at the Regional SSA Offices in the regions where the case study sites were located, and then proceeded to the Regional DDS office and one of the SSA field offices serving the local area selected. Within each of the selected localities, a field office with one of the highest absolute childhood SSI caseloads was selected.

Prospective interviewees at each level were first contacted by mail. Materials that were sent to these agency administrators included a project description; an outline of the interview topics; background information about RAND; an introductory letter from the SSA Associate Commissioner for Research, Evaluation and Statistics; and specific examples of the interview questions that would be posed during the interviews. These letters were followed by an initial telephone contact to provide further information about the study, to establish an interview time, and to identify other local contacts whenever possible.

Given the location of SSA regional and DDS office staff, all interviews with these individuals were conducted by telephone, lasting between one and two hours. We typically met with three to four staff in each SSA field office, for an average of about one hour each. In a few cases when key staff were not available during our scheduled site visit, interviews were conducted by telephone at a later date.

### **2.3.2 Identifying, Contacting and Interviewing Other Agency Staff**

In each site, we identified other public and private agencies that were likely to provide substitute income, health care, and other support services (e.g., special education programs) to children with disabilities, or that were likely to experience effects associated with the lost benefits for disabled children (e.g., child welfare agencies). Our preliminary listing of contact organizations include the local Title V Children with Special Health Care Needs agency, the department of social services and/or the local Medicaid eligibility office, the child welfare agency, and one or more other local organizations providing services to disabled children. SSA office staff at the regional and field office levels were asked to identify particularly knowledgeable agencies and providers, and specific individuals within those organizations where possible.

The process for contacting individuals and conducting interviews was similar for staff in other agencies. When possible, interviews were conducted in person during the site visit, although scheduling difficulties precluded doing so in all cases.

### **2.3.3 SSA and Other Agency Interview Content**

The goal of the interviews with SSA office staff and staff in other public and private agencies was to describe the perceptions and experiences of these individuals with respect to welfare reform, and specifically with respect to how agency operations were affected. We also sought to detail the issues that arose in the process of policy implementation, and to learn about the impact on affected families and children as perceived by administrators and local providers. The interview content and relative emphasis on particular topics varied among the providers and agencies interviewed, with the general topics outlined in Table 2.7. The interviews followed a semi-structured format, based on an interview guide with predetermined questions and probes, but with an opportunity to tailor each interview to the background and knowledge of the interviewee.

**Table 2.7**  
**Topics for Agency Case Study Interviews**

Agency/Provider Interview Topics
Description of the agency
Agency role in policy implementation
Impact on the agency and challenges
Perceptions of impact on children and families
Local policy and resource trends

In the case of regional SSA offices, the interviews focused on the broader impact of SSI eligibility provisions in welfare reform, including differences across states within the region in the implementation and impact of the 1996 legislation. Interviews with each of the DDS offices served to further identify the impact of the legislation at the regional and local level. Specific areas that were discussed with DDS staff included the operations within the specific SSA regions where our case study sites were located, including their administration of the redetermination and appeals processes for the SSI child disability program; and the impact of the legislation on the agency's operations, including the extent of the agency's involvement and coordination with other agencies and providers in the local service system.

Interviews with field office staff were more closely related to the agency's interaction with the local service system, including specific information about the impact of the legislation on the agency's operations and the extent of the agency's involvement and coordination with other agencies and providers in the local service system. SSA staff in the field offices also helped to identify and to put us in contact with state, local, and private agencies that provide services to disabled children from poor families in the case study sites.

The purpose of our interviews with local providers and agencies was largely to provide a service system context for the experiences described during our family interviews. These interviews with other public and private sector agencies served to characterize the services and programs that are available for children losing SSI benefits. Examples of areas covered include the extent to which changes in SSI eligibility rules for disabled children have affected enrollment in or the costs of state-managed and state-funded health, education, and human services programs such as the foster care/child protective service system, special education systems, and public assistance programs. Where relevant, respondents were asked to describe any impact of welfare reform provisions regarding SSI on their agency, or on their service system or in related organizations, on aspects such as caseload levels, caseload composition, average service intensity, and unmet need.

Another goal of the SSA and other agency interviews was to identify other relevant data sources for possible use in other components of the evaluation. In all cases, there was no knowledge on the part of interviewees regarding data sources beyond the SSA or

Medicaid administrative data bases already being analyzed as part of other evaluation components. In some cases, the state's own Medicaid administrative database was mentioned as a possible source of population-based data, although respondents had little knowledge of the details of these databases and how they might differ from the Medicaid databases maintained by the Health Care Financing Administration (HCFA). Thus, we do not focus on this aspect of the interview content in the remainder of the report.

## **2.4 INTERVIEWING PROTOCOLS FOR FAMILIES**

### **2.4.1 Identifying Families**

Within each case study site, we selected a clustered sample of families affected by the SSI reforms based on zip codes of residence to ensure correspondence between the experiences reported by families and the information reported by SSA offices and by local service providers. In Wayne County Michigan, the selected site was in the city of Detroit, while in Orleans County, Louisiana, the selected site was in the city of New Orleans. Hence, we refer hereafter to the five case study sites as Los Angeles, Fresno, Hartford, New Orleans, and Detroit.<sup>7</sup>

The sample was drawn from affected children as identified from the SSA Universe File (as of January 31, 1998). To capture some variability in family experiences across important child characteristics (age and type of impairment), we categorized children into strata based on the age of the child, and by three medical diagnosis classifications based on impairment type coding readily available from the Universe File. The three classifications were (1) cases coded as involving mental retardation; (2) cases coded as a mental health/psychiatric disorder (including schizophrenia and other mental disorders); and (3) cases coded as a physical health impairment (such as infectious diseases, nervous system disorders, congenital anomalies, asthma, etc.) or an impairment in the "other" or missing category. Age categories included under 6 years, age 6 to 11 years, and age 12 years and older.

We constructed 7 strata and used a different interviewing protocol (with some common core elements) for each strata. Due to the relatively small number of children age 0 to 5 years of age in the sampling frame, children 0 to 5 years identified in any medical diagnostic category were combined into one strata. The strata are (1) children 0 to 5 years (any diagnostic category), (2) children 6 to 11 years with coding for mental retardation, (3) children 6 to 11 years with a mental health/psychiatric classification, (4) children 6 to 11 years with a physical health or "other" classification, (5) children 12 to 18 years with coding for mental retardation, (6) children 12 to 18 years with a mental health/psychiatric classification, and (7) children 12 to 18 years with a physical health or "other" classification. To meet requirements for studies that are exempt from Office of

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<sup>7</sup>The order of the field work was as follows: Los Angeles, Detroit, Hartford, New Orleans, and Fresno.

Management and Budget (OMB) review, we interviewed only a small number of families in each protocol category. While we sought approximately equal numbers of respondents in each of the strata, variations in caseload distribution and family responses across the sites resulted in a range of 4 to 8 children per strata.

#### **2.4.2 Contacting Families**

Potential respondents, who were randomly selected from each local sampling frame, were initially contacted through a mailing that included a letter from SSA and a letter from RAND. The materials described the purpose and summary of the study; requested their participation and contact information; provided assurance that participation in the study would not affect their child's SSI eligibility or be divulged outside of RAND; and included a copy of the informed consent form that reviewed all elements of the study. The mailed letters were followed by a telephone call to the residence whenever a phone number was available. The purpose of this call was to answer any questions or concerns about the study, to describe the intent of the study, to solicit the family's participation, and to schedule an interview time. We emphasized to all families that their participation decisions and information provided to us would not affect their child's SSI eligibility in any way, and that they would not be identified by name.

If we reached a household by telephone where the family no longer lived but a forwarding telephone number was obtained, then an attempt was made to contact the family at this new number.

Children whose representative payee was an agency (e.g., child protective services) or institution (e.g., Medicaid institution) were excluded from the study because there was no parent whom we could contact directly. When our telephone contact with the family revealed that the child was in out-of-home foster care or institutionalized, no interview was attempted if the contacted parent said that they would not be able to answer detailed questions about the child's current status. This resulted in exclusion from the study of two children who were no longer in the care of the representative payee of record (the parent), because in each of these two cases the parent felt that he/she could not fully describe the impact of SSI income loss and the child's current status. Thus some, although not all, children in foster care were excluded from the study. Interviews were completed with one parent of a child who had very recently begun living with his other parent, and with one parent of a child currently in foster care because this parent has significant contact with her child.

In two sites (Hartford and Fresno), the parent(s) in a number of families were exclusively Spanish-speaking. Families were excluded if neither parent spoke English, and no other adult relative or friend could be identified to assist in the translation. This eliminated four families who were Spanish-only speaking. In two of these families, the only translators who could be identified were less than 18 years of age. We did interview four non-English speakers in those two sites with translation assistance by a family member or friend. Thus, the perspective of children with non-English speaking parents or guardians is represented in the sample.

### 2.4.3 Family Contacts and Response Rates

The total number of families contacted and the results of the contacts are provided in Table 2.8. The contact samples that were drawn from the sampling frames for Los Angeles, Detroit, and Hartford included approximately five families for each of the seven protocol strata. Of the families we sought to contact in August to October 1998 using the January 31, 1998 SSA Universe File, the proportion of families whom we successfully contacted by telephone (the sum of the proportion of completed interviews, refusals, Spanish only, and other cases) ranged from 14 percent in Hartford to 40 percent in Los Angeles. This involved between one and four attempted contacts per household. Due to the particularly high proportion of contacted families with disconnected or wrong phone numbers in Hartford (66 percent), an additional set of families was drawn from the sampling frame for Hartford to supplement the initial sample (with the same letter and subsequent phone contact method as with the initial sample), and the sample size of families drawn from the respective sampling frame was increased for the New Orleans and Fresno samples. For the latter two samples, the desired number of interviews was obtained without contacting all families that had received letters.

**Table 2.8**  
**Family Contacts and Response by Case Study Site**

Contact and Response Categories	Case Study Site									
	Los Angeles		Fresno		Hartford		New Orleans		Detroit	
	No.	%	No.	%	No.	%	No.	%	No.	%
Total letters mailed	40		100		86		93		62	
Total family phone contacts attempted (1+)	40		49		86		64		62	
Completed interviews	10	25	9	18	8	9	8	13	8	13
Refusal	4	10	4	8	2	2	3	5	3	5
Refusal – child not in home	1	3	0	0	0	0	0	0	1	2
Spanish only – no adult translator	0	0	2	4	2	2	0	0	0	0
Other	1 <sup>a</sup>	3	0	0	0	0	2 <sup>a,c</sup>	2	1 <sup>b</sup>	3
Disconnected/wrong number	15	38	23	47	57	66	24	38	22	35
No answer/response	9	23	11	22	17	20	27	42	27	44

**NOTES:**

<sup>a</sup> Scheduled but not completed.

<sup>b</sup> Child has died.

<sup>c</sup> Legally blind parent, in-home interview not possible.

Among families with whom a telephone contact was successfully established, most families were willing to be interviewed. As illustrated in Table 2.8, most parents with whom we were able to speak directly were willing to be interviewed, including 67 percent



(10/15) in Los Angeles, 69 percent (9/13) in Fresno, 80 percent (8/10) in Hartford, 62 percent (8/13) in New Orleans, and 67 percent (8/12) in Detroit.<sup>8</sup>

The response rates for the sample are low, although not unexpected based on the source of the information (administrative data) and the experiences of other research efforts that constructed sampling frames based on administrative data (see, for example, Strong, et al., 1998). Given the low response rates, it is likely that those families we were unable to contact may differ systematically from those families we successfully contacted. The families in the sampling frames are likely to be more residentially mobile than average, particularly given the potential income changes recently occurring for a number of these families. While several of the parents who refused an interview gave specific reasons (with examples such as the parent reporting that the child was doing fine without SSI, and that the parent was too busy to participate), it is difficult to know how nonrespondents differed from the respondents. Such low response rates may bias results when nonrespondents differ systematically from respondents, particularly if they differ on characteristics such as current income and residential stability, or the child's prior and/or current functional status.

While these are important considerations, it is also important to reemphasize that the intent of the case study design was not to draw conclusions from a representative and statistically adequate sample. The limitations in the generalizability of the findings due to the scope and selection of sites, and in the representativeness of the family interviews due to potential response bias, can be viewed in relation to the specific case study objectives. Because key objectives were to identify possible effects that other administrative and survey data do not provide, to amplify the quantitative analyses, and to help in interpreting the findings from interviews with local providers, agencies, and SSA office staff, findings from the family interviews continue to be useful for these purposes even though not necessarily representative of family experiences more broadly.

The family interviews typically lasted 45 minutes to one hour, with another 15 minutes on average devoted to making introductions and answering questions about the study. At the conclusion of the interview, respondents received a small cash payment in compensation for their time.

To minimize loss of family participants between the initial round of case studies and the second round, we requested that each family provide one or more names and contact information of relatives, neighbors, and/or close personal friends whom we could contact if the family moves during the year. Families will be re-contacted by mail at the end of 1998, and by phone in Spring 1999, to confirm their address and phone or to obtain updated information

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<sup>8</sup>These rates are calculated as the number of families willing to be interviewed as a proportion of those families whom we could successfully contact by telephone, excluding those families who were not eligible for the study based on our study exclusion criteria (i.e., child not living in the home, no English-speaking adult available for translation).

#### 2.4.4 Characteristics of Children and Families Interviewed

The sampling strata were constructed across the five sites with the objective of obtaining up to nine interviews per strata. Table 2.9 shows the distribution of the age of the children in interviewed families, by site, as of August 1996 when welfare reform was passed. Across the five sites, roughly 2 out of every 10 families interviewed had an affected child under age 6, while another 4 had a child age 6 to 11 and the remaining 4 had a child age 12 or older.

**Table 2.9**  
**Ages of Children in Interviewed Families by Case Study Site**

Age (as of 8/96)	Case Study Site											
	Los Angeles		Fresno		Hartford		New Orleans		Detroit		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Under 6 years	1	10	2	22	1	12	1	12	2	22	7	16
6 to 11 years	3	30	2	22	4	50	4	50	5	56	18	39
12 years and older	6	60	5	56	3	38	3	38	2	22	19	43
Total	10	100	9	100	8	100	8	100	9	100	44	100

As noted earlier, the caseload was divided into 7 sampling strata based on age and coded diagnosis category with a different interview protocol for each strata. The final distribution of the 44 families interviewed across these strata is shown in Table 2.10, with strata totals ranging from 4 to 8 families. As illustrated in Table 2.10, interviews with families of children with SSA coding for mental/psychiatric impairments comprised about 25 percent of the completed interviews, whereas children whose cases were coded with this impairment type comprised a somewhat higher proportion of children in the sampling frame (45 percent).

**Table 2.10**  
**Sampling Frame Totals and Interview Sample by Strata**  
**(Aggregated Across Sites)**

Age (as of 8/96)	Diagnostic Category							
	Any Diagnosis		Mental Retardation		Mental/ Psychiatric		Physical or Other	
	No.	%	No.	%	No.	%	No.	%
Sampling frame								
Under 6 years	69	9	--		--		--	
6 to 11 years	--		85	11	162	21	81	10
12 years and older	--		112	14	189	24	84	11
Interview sample								
Under 6 years	7	16	--		--		--	
6 to 11 years	--		7	16	4	9	7	16
12 years and older	--		8	18	7	16	4	9

The payee for most of the children (36 cases) was the child's mother. In two cases, the father was the payee and the guardian of the child. The child's grandmother and current guardian was the payee in five cases, and a child's great-grandmother was the current guardian and payee in one case.

Across the five sites, four interviews were conducted with Spanish-speaking parents with translation by a family member (an 18 year old former SSI beneficiary; an adult nephew; an adult daughter) and in one case by the child's former Head Start teacher and family friend.

Based on SSA administrative data used to construct the sampling frame, nine of the children in families interviewed in Los Angeles had qualified for benefits through an IFA. One of the children had qualified for benefits based on maladaptive behavior. Of the families interviewed in Detroit, eight of the children had qualified for benefits through an IFA and one had qualified for benefits through an IFA and also based on maladaptive behavior. Of the families interviewed in Hartford, seven had qualified for benefits through an IFA and one had qualified based on maladaptive behavior. Of the families interviewed in New Orleans, five had qualified through an IFA, two had qualified based on maladaptive behavior, and two had qualified through an IFA and also based on maladaptive behavior. Of the families interviewed in Fresno, seven had qualified for benefits through an IFA category, one had qualified based on maladaptive behavior, and one had qualified through an IFA and based on maladaptive behavior.

## 2.4.5 Family Interview Content

For each family interview protocol, we used semi-structured interview guides that focused on the key activities and outcomes of the 1996 policy change for childhood SSI eligibility. The first round of case studies focused on the families' experiences with eligibility redetermination and on the initial family responses to potential or experienced loss of benefits, while the second round of interviews, approximately one year later, will focus more intensively on the longer-run impact of the income loss.

While the interview content (and the emphasis within the interview) varied according to the family's strata classification, the general content of the family interviews is provided in Table 2.11. In addition to descriptive information about the child and family, the key content areas were: experiences with the redetermination process, the initial impact on family income and work participation, the impact on the child's Medicaid enrollment and access to health care, and the overall impact on the child.

**Table 2.11**  
**Topics for Family Case Study Interviews**

Family Interview Topics
Child's medical diagnostic information
Family's experience with SSI eligibility redetermination
<input type="checkbox"/> understanding of the process
<input type="checkbox"/> appeal and benefit continuation decisions
Impact on family income
<input type="checkbox"/> family income
<input type="checkbox"/> work participation and working hours of caretaker(s)
<input type="checkbox"/> use of public assistance
Family structure and changes
<input type="checkbox"/> household composition
<input type="checkbox"/> child's living arrangements
Impact on Medicaid and health care access
<input type="checkbox"/> Medicaid enrollment/access to health insurance
<input type="checkbox"/> access to medical and developmental services
Impact on the affected child
<input type="checkbox"/> child care and caretaking
<input type="checkbox"/> parent/caretaker's time spent with the child
<input type="checkbox"/> child's developmental and functional status
<input type="checkbox"/> child's school performance
<input type="checkbox"/> child's preparation for work

All findings from the family interviews are based on self-reported information. This is particularly relevant to the information provided by families about the medical diagnoses and the initially qualifying as well as current functional status of the child; about family income; and about the appeals and benefit continuation requests that they might have made following notification from SSA regarding their child's eligibility redetermination. Details provided by families about their requests for appeal, and requests for benefit

continuation under appeal, have not been compared with SSA administrative records. While attempts were made in the interviews to anchor family responses about appeals (for example) to known dates such as the issuance of the 1998 "good news" letters, there might be some discrepancies between what families reported to us and SSA records. Some discrepancies between SSA records on benefit continuation requests and family self-report were found in a beneficiary survey conducted by SSA and reported in the 1997 Commissioner's Report (SSA, December 17, 1997).

Because loss of SSI benefits will have occurred relatively recently for some families, the effects of the income loss may not be fully felt by the time of the first round of family interviews. Thus, within the various domains listed in Table 2.11, parents were asked not only about effects on the child as of the interview date, but also about changes they anticipate in the near future and how the family plans to cope with the income loss. Open-ended questions to the family provided parents with an opportunity to describe any unanticipated ways in which the child's or the family's lives have changed. Examples of the types of issues addressed in the interviews include:

- What changes have occurred in the child's health status and functional level since the loss of SSI income?
- What changes have occurred in the utilization of public health and mental health services, and in access to and use of personal medical and health-related services?
- What special school services are utilized and how has school performance been affected?
- What changes have occurred in the child's access to publicly-funded care coordination services for children with special needs such as Title V care coordination, case management, early intervention, etc.?
- What changes have occurred or are anticipated in family structure and family living arrangements and location?
- How have changes in parent employment or working hours affected the child's time with the parent, use of child care, and access to services?
- How has family income changed since the redetermination process began or termination of benefits occurred?
- Is the child or the family receiving other assistance (income, services) that substitute for the lost SSI income?
- How have parent working hours changed, if at all, since the SSI income was lost, and how are income and parent working hours expected to change in the future?

Finally, the family interviews were designed to provide a perspective on families' experiences with the redetermination and appeals process. Several questions focused on aspects of the process such as whether the parent(s) understood the materials provided by SSA, what problems occurred, where the parent got information about this process, and from whom the parent received help in decisions about the appeal process. We also attempted to determine why the family decided to appeal or not to appeal the termination.

## **2.6 STRENGTHS AND LIMITATIONS OF CASE STUDY METHODOLOGY**

The case study methodology outlined in this section is designed to provide insight into the impact of the 1996 welfare reform legislation on the families and children affected by the loss of SSI income. The descriptive, qualitative methods employed in the semi-structured interviews with agency staff and with families are designed to complement other qualitative components of the evaluation (see Rogowski, et al., 1998, for additional detail on the other evaluation components). The case study interviews will complement the other components of the evaluation in several ways. They may identify perceptions or experiences with effects of the legislation that are not possible to analyze with other administrative or survey data. They also may amplify or deepen our understanding of results from the statistical modeling in administrative and survey data. The case studies also provide more immediate feedback on the impact of the program changes than is possible with the analyses of caseloads and costs and other secondary data. The interviews with families also may be helpful in interpreting the findings from interviews with local service providers, and vice versa.

As stated elsewhere in the report, the procedures used to select sites and to sample participant families were designed to provide as much range in perceptions and experiences as possible across the sites visited. While the case studies are based on small samples by design, we have implemented a more purposeful sampling procedure (both in terms of selecting sites to visit—states and counties—and respondents to interview) to ensure that there is interesting variation in the characteristics of the sites and respondents in the final sample. We believe that this variation is important for ensuring that the portrait we obtain of affected families and providers reflects the richest set of experiences and perceptions as possible. While some of the outcomes are amenable to summary in quantitative form (e.g., the percentage of families among the total interviewed where a family member reported an increased level of work effort in response to the loss of cash benefits), most results that are presented in the sections that follow will be summarized in a more qualitative form (e.g., noting when a particular outcome was prevalent or more rare, and describing the range of outcomes raised by families).

Moreover, it is important to recognize that the case studies are not intended to provide a statistically representative sample of affected families or providers. The results are not intended to have the same statistical properties of a larger probability sample. For that reason, we do not believe it is appropriate to attach standard errors to any quantitative data resulting from the case study interviews as one would in an analysis of a larger probability sample. As the results of the interviews are presented and interpreted, it is therefore important to keep in mind that the results are not intended to be statistically

representative of the specific case study site, state, or population from which the sample was drawn. Rather, the case study results can help to portray in more detail some of the range in and nature of experiences among families and providers as a result of welfare reform.

### **3. SITE VISIT SUMMARY: LOS ANGELES, CALIFORNIA**

#### **3.1 INTRODUCTION**

California was selected as a case study site due to its high volume of affected child SSI beneficiaries, its high penetration of Medicaid managed care, and its demographic characteristics including the presence of urban counties as well as some rural counties with significant child SSI caseloads. We visited Los Angeles, California during the weeks of August 17 and August 24, 1998. We interviewed a total of ten families in addition to 23 individuals in 14 different agencies.

The State of California ranks first among states in the total number of children under age 18 (at 8.6 million in 1996). In terms of SSI participation in August 1996, California ranked second among states in the total number of children on SSI but ranked much lower in the proportion of children on SSI (ranked 38 at 0.9 percent of children). California ranks seventh among states in the volume of child SSI beneficiaries with IFA (who represent 14.2 percent of the child caseload) and second among states in the volume of child SSI recipients with maladaptive behavior (who represent 6.1 percent of the child caseload).

Los Angeles County ranks highest among counties in California in the total number of child SSI beneficiaries, total IFA and maladaptive cases (3,611), total cases subject to redetermination (5,535), and the total cases terminated with no appeal pending as of January 1998 (1,071). Los Angeles County ranked lower than a number of other counties in the percent completed of those cases subject to redetermination (ranked 15 of 58 counties)—likely due to the size of Los Angeles County’s caseload—and in the percent of cases terminated with no appeal pending (ranked 13).

California is not as far along in implementing welfare reform as states such as Michigan and Connecticut. While California had waivers that allowed reforms prior to the statewide welfare reforms that are now underway, the statewide implementation of TANF began in January 1998. California’s welfare program known as CalWORKs (California Work Opportunity and Responsibility to Kids) offers transitional child care and transitional Medicaid for longer than 12 months for welfare beneficiaries who stop receiving cash assistance.

In terms of Medicaid coverage, California’s coverage of low-income children has been expanded through the State’s Title XXI State Child Health Insurance Program. Income eligibility for Medicaid has been extended to 100 percent FPL up to age 18 years, and the new, non-Medicaid state program (called Healthy Families) extends coverage for children 1 to 18 years up to 200 percent FPL. Cost-sharing for the state employee package (supplemented with vision and dental benefits) that is offered under Healthy Families applies only to children with family income above 100 percent FPL, with monthly premiums adjusted by family size and plan type. Managed care arrangements are required



for the majority of children, but in most counties (including Los Angeles), child SSI beneficiaries are not required to enroll in prepaid health plans (PHPs).

In the sections that follow, we first discuss the results of our interviews with agency staff at the SSA regional office, the DDS office and the SSA field office. We then summarize the interviews with Medicaid and other public and private agency staff. Finally, we conclude with a summary of the family interviews in Los Angeles.

## **3.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES**

### **3.2.1 SSA Regional Office (Richmond, California)**

We interviewed an administrator in the SSA Regional Office in Richmond, California who supervises childhood disability issues for the region. The Regional Office has approximately 100 staff, with the Center for Disability having about 12 to 13 program specialists. There is one primary person responsible for policies and procedures, with one person devoting 10 percent time and an assistant working on case control and management information systems (MIS). The region covers four states (Arizona, California, Hawaii, Nevada) and Guam and the North Mariana Islands.

#### ***Role in Policy Implementation***

The Regional Office has provided support and guidance regarding the processing of claims, claims development, decision-making processes, and support for medical policy and adjudication of cases.

There was a significant level of training for the field offices. The Regional Office was directly involved in the nationwide training on the new regulations in late Fall/early Winter of 1996-1997. Following the Commissioner's Top-to-Bottom review in Fall 1997, a national training was done again. For the DDS level, the office had to make sure that all staff were apprised of the training and new materials, and also that training was being provided within the DDS. Responsibilities for the field office level included ensuring that the field offices follow procedures for due process, for preparing cases for DDS, and for case processing.

The Regional Office has not played a role with the Medicaid related issues. HCFA and the state Medicaid agencies are handling the implementation of the 1997 grandfathering provisions. The Regional Office does have a working cooperative relationship with the California Department of Social Services, due to the geographic proximity of California's state offices relative to the other states.

### ***Agency Impact and Challenges***

Roles have not changed since the 1996 welfare reform, particularly when compared to the changes that occurred after the *Zebley* decision.<sup>9</sup> Prior to *Zebley* there was not a need for the same level of focus on childhood cases.

**Staffing and training.** One of the most significant challenges in implementing the PRWORA has been the issue of keeping field offices straight on the types of cases they are working on and how to respond to them. For example, the term “redetermination” was used for the process of assessing medical eligibility, but also was used for the non-medical processes. Some of the difficulties experienced so far include some tendency of field offices to treat redetermination cases like the continuing disability review (CDR) process. In this example, the use of the incorrect forms then results in confusion at the DDS level. The difference between the redetermination and the CDR processes has been enough to keep the offices off balance, and this is occurring as CDRs have been initiated and the re-reviews from the 1997 Top-to-Bottom review are underway.

The volume of cases within SSA office may have several effects in terms of the workload and efficiency. Offices with small caseloads have had the capacity to put more effort into getting the cooperation of payees in the redetermination process. On the other hand, offices that have a higher volume of cases appeared to become comfortable with the new rules more quickly.

**Implementation.** Some of the problems being observed stem from the ongoing policy development process. The Regional Office is attempting to make sure that the policies and procedures are made clear to SSA staff at all levels, as these policies evolve or are modified.

Cases of children with combinations of impairments—particular cognitive and speech and language impairments—have been more difficult to handle and this has been a focus of guidance and clarification to make sure that the combination of effects is considered.

In terms of case processing, late filing of appeals has been one area where problems have occurred. In some instances, a filing might have been denied for coming more than 10 days after the date of the letter, yet the filing occurred within 10 days of the postmark. The appeals process has been an area requiring ongoing oversight from the Regional Office due to anecdotal reports of cases being mishandled. There was some anecdotal suggestion of families being overtly discouraged by SSA staff from filing appeals. It is not

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<sup>9</sup>The February 1990 Supreme Court decision *Sullivan v. Zebley* found that the failure to provide individual assessment of function in children violated the SSI statutes, as did the failure to adequately evaluate children with impairments that were not included in medical listings, or with combinations of impairments that did not fulfill all criteria for any one listed impairment (Rogowski et al 1998; *Sullivan v. Zebley*).

clear to administrators what would motivate this activity if it occurred, and efforts have been underway to address the issue.

It is difficult to know how the volume of new applications has been affected by the change in childhood disability criteria. This is in part because of the collateral effects of other provisions of welfare reform, and because of changing economic conditions. There has been a slight decline in new claims in the post welfare reform period. The Regional Office has estimated that childhood applications are down approximately 10 percent from previous years. No change in the content or quality of medical evidence in new applications has been identified, however.

Advocacy efforts have not had a major local impact on the childhood SSI cases. The San Francisco National Center for Youth Law (NCYL) is an example of a local advocacy group that has been a major player in SSI issues since the *Zebley* decision and has been very involved in outreach and advocacy at the national level.

### ***Caseload Status***

Most redetermination cases have been processed at this time with about 98 percent fully processed. The remaining cases are those in which offices are examining whether they are subject to redetermination or whether eligibility was lost due to non-medical reasons.

About 60 percent of the cases have been continued at the initial level. The status of the appeals process is difficult to estimate. On the Supplemental Security Record, there is wide variation in how the appeals status of a case is recorded. For the appeals made following the 1997 notices to families, most cases are through the reconsideration step and the face-to-face DDS hearings. A significant number of cases are at the next level of reconsideration (the Office of Hearings and Appeals (OHA)). Based on the new appeal opportunity offered by SSA in March 1998, about 50 percent are still pending in the DDS at the reconsideration step.

### ***Differences Across States***

In terms of differences across states, the Regional Office administrator was most familiar with California. California has been most vocal in asking for assistance and information. Across states, the DDS organizational structure and patterns of resource use have affected the impact on DDS offices. In the three smaller states, the medical consultant staff at the DDS includes psychologists, and these states have been more comfortable in interpreting psychological testing, which is a big component of the redeterminations. For a variety of reasons, in California there were no psychologists in the DDS structure. Instead there were only psychiatrists, who mostly specialized in adults. There was thus more difficulty in California in interpreting evidence from tests. This affected how the states approached their workloads as well as their case processing.

In terms of comparisons with other states nationally, California has had a lower number of SSI claims among its population relative to states such as Louisiana. Differences such as economic factors and public agency outreach efforts across counties in California, and across different states in the region, may contribute to differences in policy impact. For example, in California the bulk of the childhood cases are in the Central Valley (e.g., Fresno).

There also may be differences across California's counties in the extent to which public agencies aggressively pursue SSI applications for children receiving services from those agencies. An effort to shift county and state costs to federal programs is one rationale for efforts by child protective service agencies, for example, to encourage SSI applications, which coincides with budget shifts from the state to county levels. A number of counties have contracted with private agencies to help them enroll children in SSI. Los Angeles County is one area that has implemented special projects with specific agencies regarding referral to SSA for SSI enrollment. In terms of state differences, Hawaii and Nevada have not made concerted organized efforts to refer children from state or county rolls to SSI. There also have been outreach efforts (joint ventures between DDS, field SSA offices, and the Bureau of Indian Affairs) for Indian reservations in Arizona and Hawaii to enroll eligible adults and children in SSI.

In terms of differential impact across population groups, there may be a particular effect on the immigrant population. Even eligible children could be affected if their parents have undocumented status and believe that the Immigration and Naturalization Service (INS) "public charge" provisions could apply to them.<sup>10</sup> The administrator we interviewed speculated that this could affect some parents' proclivity to file new applications, to appeal terminations, and to request benefit continuation during appeal, although there is no specific evidence that this is happening.

### **3.2.2 SSA Disability Determination Services (DDS), Los Angeles**

We interviewed a staff member in case processing and operations, and a DHO, in a Los Angeles DDS office. There are approximately 125 staff in the DDS office, including professional staff, physicians, and other staff. About 42 professional staff have involvement with the childhood cases along with 30 clerical staff. There are five teams that include a unit manager, two medical consultants, eight analysts, and four to five

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<sup>10</sup> An INS "public charge" refers to a non-citizen who is or who is likely to become primarily dependent on the government for income support on long term care (U.S. Department of Justice, May 25, 1999). Public charge status could conceivably have adverse immigration consequences for the non-citizen as well as financial obligations for the non-citizen's U.S. sponsor (SSA May 26, 1999). Welfare reform and recent immigration laws may cause concern among non-citizens and their families that causes them to forgo public benefits for which they are eligible (U.S. Department of Justice, May 25, 1999). Public charge guidance issued by INS in May 1999 identified income maintenance from TANF, SSI, and State cash assistance as subject to public charge consideration but not SCHIP or Medicaid (with the exception of long term care).

clerical staff. The DDS office has about eight disability hearings officers (DHOs), out of a total of approximately 32 DHOs in Los Angeles County. About one-third of the cases of the DHO we interviewed are childhood cases.

### ***Role in Policy Implementation***

The DDS reviews the medical files and requests medical information and/or purchases a consultative exam when necessary, and contacts third parties such as children's schools and physicians to the extent necessary. The analyst then writes up the completed case file. The review of the file results in a decision that can be appealed at the initial appeals level.

Disability hearings officers conduct Goldberg-Kelly termination hearings for children as well as adults whose benefits may ceased. In the reconsideration Administrative Law Judge (ALJ) proceeding conducted within the Disability Hearing Unit (DHU), the family is "sworn in" and sometimes is accompanied by an attorney. The DHOs conduct a face-to-face interview with the representative payee and with the child as well. The DHO we interviewed estimated that the child attends the hearing in about 97 percent of cases. After reviewing the file prior to the hearing, the DHO begins the hearing by describing the status of the case, describing the process, and emphasizing the need for the payee to come to the SSA offices to complete the necessary steps of the eligibility determination process. Often families want to immediately explain their case, and sometimes they bring in additional facts and documentation for the DHO to consider when the file is reviewed following the hearing.

The DHO emphasized that cases are not terminated automatically when the medical evidence is not adequate to make an informed eligibility decision. In situations in which the parents are uncooperative, the DDS continues to contact third parties (social workers, schools) to obtain the necessary evidence. It is recognized that the parents themselves may have problems that interfere with their capacity to respond to the case proceedings. The DHO we interviewed stressed the efforts made at the hearing level to track down the necessary information to make an informed determination.

The hearing generally lasts about one hour but range up to two hours in length, and the time spend by the DHO to adjudicate the case can range up to 10 hours for more complex cases. The DHO asks questions about the child's personal life, the child's school, participation in therapies outside of school, and other questions. Some questions are directed at the child and others at the parent/payee in attendance. The DHO has asked parents to compare the child to neighborhood children. The hearing enables the DHOs to learn whether children who are enrolled in physical education classes in school actually participate or not, and permits direct discussion with the children about how they are affected by the problem.

For cases in which eligibility is ceased after the hearing and the payee chooses to appeal, the cases are sent through DDS to the OHA for the second level of appeal.

The DHO we interviewed explained that California historically has conducted disability evaluations for its Medicaid program (Medi-Cal) according to the same federal standard of disability with some modifications. There are two offices in California (in Oakland and Los Angeles) that used paper review of case information to make disability determinations. The DHO did not know what level of familiarity staff in the program have with pre-PRWORA childhood SSI eligibility .

### ***Agency Impact and Challenges***

**Staffing and training.** An initial implementation issue was the handling of mental exams in childhood cases. In the beginning, differentiating cognitive and social functioning was an issue, although the issues are clearer now. In comparison to the pre-welfare reform period, more information now is needed from schools and particularly on speech and language abilities. More functional information is now required, as is the Individualized Education Plan (IEP) from schools and information from other agencies.<sup>11</sup>

**Implementation.** Some challenges are related to the emphasis on testing. This has involved the training on interpretation of psychological testing because there is a psychiatrist on staff at the DDS but no psychologists. The DDS has not needed new medical staff to process the caseload, however, because the DDS has pediatricians on staff and has access to a physician (in Fresno) who works on speech and language issues.

Overall, the staff reported that processing time has increased for childhood cases; these cases can be more difficult to adjudicate and involve multiple attempts to get the necessary information.

One staff member we interviewed stated that most of the cases reviewed so far have been children with Attention Deficit Disorder (ADD)/Attention Deficit Hyperactivity Disorder (ADHD) or learning disability. Often the childhood cases that are redetermined under the new disability definition are “borderline” cases in which it is very helpful for the DHO to meet and talk to the child directly, and this interaction is encouraged.

The Los Angeles DDS office took over a large part of the caseload from the Central Valley cases in Fresno due to the overwhelming redetermination caseloads in that area. The DHO suggested that Fresno’s large caseload was partly attributable to economic reasons; some people move inland to the Central Valley because it is less expensive and because seasonal and part time work required for peoples’ disabilities is easier to obtain.

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<sup>11</sup>The Education for All Handicapped Children Act (P.L. 94-142) passed in 1975 required that schools develop individualized education plans (IEPs) for children with disabilities; as an education and service plan for the child, the IEP must be developed with parent involvement and based on child assessment (Shonkoff & Meisels, 1990).

### ***Experiences with Family Response and Impact***

One administrator indicated that in most cases when families appeal, they are depending on the SSI for their household income. It was estimated that approximately 80 percent of the payees request benefit continuation during their appeals. The DHO we interviewed believed that those parents who do not elect benefit continuation tend to be cases in which the parent believed that the child would not ultimately be found eligible.

At the hearings, most parents appear to understand what is happening to their child's case, but a few parents state that they do not understand the process. One misconception has occurred among some families who have had involvement with family court. These parents sometimes believe that the child should not be brought to the SSA hearing because they are told not to bring the child to the family court proceedings.

Cases of children in child protective services do not appear to have differential outcomes in their cases; some children in foster care show significant functional improvement because they have access to special programs. This underscores how child cases are different than adult cases because there often is clear evidence that receiving the SSI benefits has helped the child and family. The DHO described one case in which a twin who had had viral meningitis in infancy and resulting speech delays had received SSI benefits, speech therapy, and preschool education, and had higher functioning than the other twin without any disability.

### **3.2.3 SSA District Office (Los Angeles)**

We interviewed a supervisor for disability claims and a service representative in a Los Angeles County district office. The district office currently has 46 staff, which is down from a total of 80 to 90 staff prior to welfare reform. There are three full-time persons who were brought into the office as a result of the welfare reform eligibility changes. The third full-time, temporary person was brought into the agency in October 1996.

### ***Role in Policy Implementation***

The district office staff has worked with parents to complete the paperwork, assembling provider names and records and sometimes reconstructing the medical record from when the child first received SSI. The DDS procured the necessary medical and functional information about the children whose cases are being redetermined. Staff perceived that the DDS was doing everything possible to be cautious in handling the childhood cases. Once the case returns from the DDS, the claims representatives determine the level of payment and process the benefits. The supervisor felt that the staff was proactive in helping to get benefits continued for any parent who requested benefit continuation.

The service representative has occasional contact with the Department of Public Social Services (DPSS) regarding the Medicaid status of children. In general, parents are

referred to DPSS if they experience problems with Medicaid eligibility or enrollment issues. In some instances the claims representative (CR) and a specific contact person the SSA staff can call at the local DPSS work together so that the Medicaid eligibility of a child is not affected.

District office staff also worked to help those children who were born in the U.S. to establish their proof of citizenship. The citizenship issues are much more significant for adult beneficiaries (particularly seniors) and have not affected many children directly.

### ***Agency Impact and Challenges***

The caseload handled by the office and the paperwork burden did increase as a result of the changes. The implementation of welfare reform did not have a major impact on the office operations, however. The service representative measured progress with the caseload based on the number of carts filled with case files.

### ***Experiences with Family Response and Impact***

Almost all families contacted the district office when the first SSI check did not arrive, and came in to complete the necessary paperwork to appeal. Because families now receive the funds through direct deposit, they responded when the check was not deposited, and incorrect address information was not a problem in terms of getting families to respond.

In terms of appeals, the CR perceived that most parents had appealed when the case was initially denied. Most of the redetermined cases involved children with learning disabilities, and the staff felt that nearly all of these cases were denied. The appeals opportunities offered to families seemed to guarantee that families would appeal, and no particular characteristics of families who did not appeal were known. Most families continued to receive benefits during the appeals period.

While the claims representatives handle only the initial part of disability claims, many parents contact the field office for information about their child's case. Even when the case is being handled at DDS, parents seem to feel more comfortable asking someone with whom they are familiar. Families seem aware of other services that are available to them and rarely ask for referrals or help with finding needed services. The staff we interviewed was not aware of any formal advocacy activities or family legal assistance underway for the affected children, and did not have partnerships with community groups.

## **3.3 SUMMARY OF INTERVIEW WITH MEDICAID AGENCY**

We spoke with two administrators in the Medi-Cal (Medicaid) Program Eligibility Branch of the California Department of Health Services. One of the administrators handles eligibility for individuals losing SSI-linked Medicaid eligibility. The Medi-Cal Program Eligibility Branch is housed in the State Department of Health Services. The



new Title XXI State Child Health Insurance Program (SCHIP), called "Healthy Families" in California, is administered by a separate state agency called the Managed Risk Medical Insurance Board.

### ***Role in Policy Implementation***

According to the administrators we interviewed, the Medi-Cal agency had not yet completed the protocols and the necessary programming to handle the grandfathered group of children who may lose SSI linked Medicaid coverage. It was not known when this will be completed. Healthy Families and California's TANF program—California Work Opportunity and Responsibility to Kids (CalWORKs)—are both under implementation and priority programs, which is causing other projects to be pushed back.

The protocol is to put children dropped from SSI into a tracking process; if an appeal is pending, then they keep the child on Medicaid through the appeals process. Currently children are being maintained on Medicaid, so they should not be losing benefits during this time. Some of the children may be receiving Medicaid through a different eligibility category, however, such as families who went to other programs such as TANF. In principle, many of the children would continue to be Medicaid eligible due to the Medicaid eligibility expansions.

Statewide figures show that the grandfathered group currently includes 5,231 children (this is the total from the last tape received from SSA). So far, three tapes have been received from SSA. The information that is normally received from SSA, on a monthly basis, includes updates on SSI recipients who lose SSI benefits, and their payment status.

It was thought that the language in the initial notice to families about benefits termination states that the child can retain Medicaid benefits. However, the final appeals notice when benefits are ultimately denied does not say anything about this, so far as the staff knows. It was not known whether families are notified about Medicaid eligibility options at the end of the appeals process.

### ***Agency Impact and Challenges***

Children whose cases are under appeal should not be losing Medicaid coverage. If the children's cases are not appealed, however, then they might have lost Medicaid. One challenge is that the appeals status information provided to Medi-Cal by SSA is several months behind or not updated at all. While Medi-Cal eligibility should continue while the child's case is under appeal, the appeals status does not get updated, and the Medi-Cal agency does not know the child's level of appeal. Thus all that is known to the Medi-Cal Eligibility Branch is that the child is no longer receiving SSI cash benefits. The cash assistance indicator tells Medi-Cal that the child should be eligible. It is possible that these children could be taken off the Medi-Cal rolls, or that their families could be made to go through another Medicaid eligibility redetermination process.

It is not possible at this time to estimate the impact of the 1996 welfare reform or the 1997 Balanced Budget Act on the agency, in terms of changes to child disability and related Medicaid coverage, because the agency has not yet implemented new protocols. They do not know what levels of resource intensity will be involved because they have not yet finalized the protocols.

There is a state program that is expected to make the medical determinations to determine whether children in the grandfathered group still meet pre-PRWORA SSI eligibility criteria (with respect to their disability). This program is the State Program Disability Evaluation Division (DED) and has a contract with the California Dept. of Social Services to assess disability for the Medicaid program. There are two regional offices, in Los Angeles and in Oakland. The client fills out paperwork and this paperwork goes to one of the two offices. There are no direct exams with the medical record review, and so it differs from SSA eligibility determinations in this way.

Once the system is set up, program administrators expect that several forms will be sent to families for them to complete. The families would not need to go to the county DPSS offices to complete the paperwork and instead can mail the completed forms.

At the state, it will be possible to track children's Medicaid eligibility status, but they cannot do it yet for the SSI population because they do not have the programming in place. It will be possible to use current data systems to track any children affected by the new SSI childhood disability law who move into the Title XXI state-only SCHIP program (Healthy Families). In contrast, counties cannot track eligibility status (such as children formerly on SSI who move to other eligibility groups) other than doing it manually. Thus it is possible that children could fall through the cracks locally. The State program expects that counties are aware of the "grandfathered" cohort of children.

### **3.4 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES**

#### **3.4.1 Los Angeles County Department of Public Social Services (DPSS)**

We interviewed two administrators in the Los Angeles County DPSS in the Medi-Cal Program, and one administrator with management responsibilities for the CalWORKs "welfare-to-work" program. The Los Angeles County DPSS is the second-largest county-operated welfare department in the U.S. There are approximately 38 DPSS offices in Los Angeles County.

#### ***Role in Policy Implementation***

DPSS district offices provide intake and casework services throughout the county on a regional basis. The Medi-Cal program is administered by the State Department of Health Services, and eligibility as well as medical claims are processed at the state level. Consequently the Los Angeles County DPSS Medi-Cal Program has a limited role in handling children's eligibility for Medi-Cal.

### ***Response to the Policy Change***

SSI changes in welfare reform had not had any observable effects on the local DPSS offices. The offices are undergoing significant changes to their welfare programs as a result of the broader welfare reform changes. A primary activity in response to the SSI changes involves conducting eligibility determinations for cash assistance in those families who seek to add the former SSI child recipient to the family cash grant.

### ***Observations of Family Impact***

The administrators in the DPSS Medi-Cal Program were not aware of any specific or systematic problems that had occurred in terms of Medicaid eligibility and enrollment for children affected specifically by the SSI provisions of welfare reform.

County DPSS has found that a number of families whose children are covered by Medi-Cal appear not to be aware of the child's eligibility and enrollment, however. Some evidence of this was found as the State of California implemented its Title XXI SCHIP, called Healthy Families. Application statistics during the first few months of enrollment in 1998 indicated that up to one-third of the children for whom parents applied to Healthy Families already were enrolled in Medi-Cal. State statistics for the initial four months of the program in 1998 indicate that eight percent of child applicants found to be ineligible were already enrolled in Medi-Cal.

The CalWORKs administrator noted that parents who are the caretakers of a child with disabilities can obtain exemptions from mandatory work requirements under the new welfare-to-work provisions. The regulations allow exemptions based on caring for an "ill or incapacitated" member of the household, as long as the welfare department can determine that the caretaking responsibilities impair the recipient's ability to participate in welfare-to-work activities or to be regularly employed. The administrator believed that this determination would be made by DPSS caseworkers on a case-by-case basis but did not know what specific criteria might be used, or whether a child's receiving or not receiving SSI was relevant to this type of exemption determination.

### **3.4.2 Los Angeles County Department of Mental Health, Children and Youth Services**

We interviewed an administrator in the Children and Youth Services Bureau in the Los Angeles County Department of Mental Health (DMH). The Department of Mental Health, Children and Youth Services Bureau served approximately 22,000 children in 1997-1998. The target population in Los Angeles County's child and youth population includes severely emotionally disturbed children and youth; children in inpatient psychiatric facilities; and handicapped students who are referred to DMH by local education institutions as part of state law requiring a DMH role for children in special education. The DMH is required to provide mental health assessments to children based on the child's IEP. About 1,000 children receiving services in DMH have also received SSI; no figures are readily available on the number whose eligibility is undergoing redetermination.

It is estimated that DMH meets only about 20 percent of the need for child mental health services.

The DMH has 8 programs that are co-located in the Department of Public Social Services to help mentally ill persons apply for SSI. DPSS workers go out to DMH mental health clinics to help potentially eligible persons complete applications for Medicaid, and it is possible that some of this effort translates into referrals to SSI as well. Medicaid is a significant funding stream for DMH and renders children eligible for a range of services. An important mechanism for enrolling individuals in Medicaid has been using DMH funds to support eligibility workers going to clinics, rather than requiring potentially eligible clients to go to DPSS offices. Matching funds make DMH funding of these eligibility workers very cost effective.

Having a similar arrangement with SSA was mentioned as something that would be a positive step for children as well as for adults, given that DMH already is conducting financial screening of the children. SSA is a completely different governmental agency whereas DMH and DPSS are both part of the county system, the administrator we interviewed indicated that relationships (fiscal and otherwise) between county agencies generally were easier to establish than with federal and other agencies, given the common county governance structure.

### ***Role in Policy Implementation***

The DMH has arrangements with 81 separate school districts to provide mental health services for children in special education programs in those school districts. The AB 3632 (special education) program in California is a small part of the total child and youth population served by DMH; for these children, DMH is mandated by federal and state law to provide the assessment and case management services for children, and to participate in the IEP of children. In terms of children identified in special education as having severe emotional disturbance (SED), the school makes a determination that the child is severely emotionally disturbed, and this triggers a referral to mental health to determine whether the child needs mental health services to benefit from education. However, most of these children are not eligible for SSI because about 80 to 90 percent are not income-eligible. Many of the children come from higher income families with parents who can be strong advocates, because parent advocacy is often needed for the referral to special education with involvement of the DMH.

DMH has a staff of psychiatrists, psychologists, social workers, nurses, and others in clinical staff who are primary therapists and become involved in SSI evaluations, or that add information to the evaluations that SSA conducts.

### ***Response to the Policy Change***

There has been a concerted effort on the part of DMH to respond to the childhood SSI eligibility changes. DMH worked with a local legal advocacy and assistance organization called "Mental Health Advocacy" in putting together information designed to

educate clinicians in the DMH system about SSI eligibility changes pursuant to welfare reform, and designed to help them strengthen their evaluations to support eligibility determinations for the affected children. This has created more work that takes away from other activities that DMH could be doing, although this has not caused any significant stresses on the agency that would require resources to be shifted within the agency, or that have come to the attention of the administration in general.

### ***Observations of Family Impact***

The administrator we interviewed suggested that the recent Zebley child eligibility expansion had created new opportunities for families, and that welfare reform changes would take away some of these new opportunities for access to health services, mental health services, and housing/other family expenses. Some families might feel a stronger incentive to move a child from home to an out-of-home placement, because an out-of-home placement presents less of a financial burden for families. According to the administrator, a situation is created where the only way some families can afford the services is through out-of-home placement.

Another impact is related to California's implementation of the Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. According to the administrator, a lawsuit in California was recently settled regarding California's incomplete implementation of the EPSDT program, which included mental health services. The administrator explained how this had created an open-ended entitlement for mental health services for child Medicaid beneficiaries, for the first time. Children who were on SSI would automatically qualify for the expanded mental health care benefits, and not being eligible for SSI removed one way of extending Medicaid eligibility (and thus expanded EPSDT benefits) to a child who would not otherwise qualify for Medicaid.

The third impact raised by the administrator is related to the transition from childhood to adulthood. The administrator we interviewed stated that many severely ill children in the foster care system have SSI income or at least Medicaid coverage. When they reach age 18, their option is to apply for SSI, and it has been much easier to have the SSI continued if they have been eligible as children, than it is to get SSI as an adult, if they have not received it before age 18. The administrator suggested that the transition into the adult SSI program could become more difficult and require an appeals process no matter how disabled the child is. Extra steps or effort required on the part of families could pose barriers to following through with the process. The Department of Mental Health has a contract with Mental Health Advocacy and with others to make sure that this process is followed up, but these steps may not reach everybody.

The administrator we interviewed did not have specific knowledge about how well informed families are about the PRWORA changes, and did not have any direct knowledge of how many families have successfully (or not successfully) accessed advocacy help and legal assistance, if needed.

### ***Local Policy/Resource Trends***

Traditionally, mental health benefits through the fee-for-service Medicaid program have been administered in California by the State Department of Health Services. Consolidation of Medicaid mental health services has been occurring for the past several years as the program is transitioned to a locally-administered, managed care system. In 1998, responsibility for fee-for-service Medicaid professional psychiatric and outpatient psychology services was transferred to the County DMH in Los Angeles.

The administrator pointed out that the Healthy Families program is having a significant impact on DMH and the provision of mental health services. There is potential for this program to extend medical coverage for children who might not otherwise be covered, and there is also important potential with respect to mental health services specifically. In the Healthy Families program, children who meet medical necessity criteria are eligible for two different levels of mental health care. The first level is the basic mental health benefit within the contracting prepaid health plan (PHP) (20 outpatient and 30 inpatient visits per year per child), and by statute the health plans are required to refer children with severe emotional disturbance to the county mental health department, which is able to draw down a 65/66 percent federal participation match for the services, whereas in the past, 100 percent of the costs would have come from the county general fund. The administrator described this as a major benefit for the county mental health system and for the children who will benefit.

DMH also has relationships with the PHPs in Los Angeles County to manage the Medicaid mental health care benefit “carve-out” of services. Also, there are relationships with the PHPs that are participating in Healthy Families to manage the mental health services; because the enrollment in Healthy Families has just begun, DMH has not yet received referrals and the system is as yet untested.

### **3.4.3 Title V Children with Special Health Needs**

We interviewed an administrator of the Children’s Medical Services division of the Los Angeles County Department of Public Health, which administers the Title V Children with Special Health Needs program (California Children Services, or CCS). The scope of CCS-eligible conditions in California is generous relative to counterpart programs in other states. For approximately 30,000 children in Los Angeles County who are enrolled in Medicaid and CCS, services provided for the CCS condition are pre-authorized by the local CCS agency. CCS also covers medical services for children with limited or no health care coverage who are ineligible for Medicaid.

### ***Role in Policy Implementation***

The County CCS program frequently assists families in providing the medical documentation necessary for an SSI eligibility determination. The CCS agency also has provided referral information to families who may be eligible for income support programs. This referral activity generally is done as part of the financial intake process;

potential SSI eligibility can be assessed at the same time that intake staff is making an income eligibility determination for CCS.

The State Children's Medical Services division held a two-day meeting in Los Angeles for program administrators, during the end of 1997, which was conducted in partnership with SSA representatives. The meeting was attended by a number of county CCS offices and by community groups. This meeting was designed to provide CCS offices with the necessary background information so that they could ensure that eligible children continued to receive SSI income. The purpose of this meeting was to provide background about the policy change, to inform agencies about the changes, and to emphasize the importance of the CCS agencies' roles in helping to provide the medical documentation necessary to re-evaluate childhood cases.

The CCS program does not have formal relationships with SSA offices but has worked with SSA field offices that are close to CCS administrative headquarters; this has largely involved getting materials periodically from SSA about eligibility and other policies, and being on the mailing lists.

### ***Response to the Policy Change***

In response to the childhood eligibility changes, information from the regional meeting was shared with the CCS staff who complete the income eligibility determinations for the CCS program. No impact on the agency has been identified.

### ***Observations of Family Impact***

The viewpoint of State Children's Medical Services during the regional meeting in 1997 was that there would be little impact on children in the CCS program, and projections were that no CCS-enrolled children would lose SSI following the redetermination process. The importance of complying with SSA requests for medical documentation was emphasized so that no children lost SSI due to inadequate documentation of their condition or functional status.

While the impact was thought to be minimal, the CCS administrator did identify the loss of Medicaid eligibility as a potential outcome of children losing SSI benefits. There also is some possibility that Medicaid interruptions might occur for children, largely due to the challenge to families in keeping up with the eligibility process. While income fluctuations can cause Medicaid eligibility changes, the difficulty that families can have in following up with eligibility determination processes is a more likely cause of lapses in eligibility/enrollment.

### ***Local Policy/Resource Trends***

Children with CCS-eligible conditions are permitted (at least technically) to completely disenroll from a PHP and receive all services on a fee-for-service basis, if there

is sufficient cause. The CCS administrator was not aware of any children who had taken advantage of this option and did not know whether many families and providers are aware of it. Thus there still remains an option for some children with CCS conditions to remain in the fee-for-service Medicaid system even if they no longer receive SSI and are thus transitioned to a mandatory managed care Medicaid eligibility group.

#### **3.4.4 Child Welfare - Los Angeles Department of Children and Family Services**

We interviewed an administrator in the budget and fiscal services division of the Department of Children and Family Services, who is also a representative payee for some children in out-of-home placements. The Department of Children and Family Services (DCFS) has approximately 5,600 staff positions and a budget of nearly \$1 billion. DCFS operates eight regional offices and contracts with private agencies and foster homes for the care of nearly 50,000 children in out-of-home placements in Los Angeles County. DCFS manages a family preservation network in addition to a child abuse hotline and adoption assistance program.

##### ***Roles for Children With Disabilities***

As a representative payee for a number of children in foster care arrangements, the DCFS Revenue Enhancement division has responsibilities for responding to the redetermination notices and any other requests for financial or medical documentation received from SSA. According to the administrator we interviewed, DCFS has sought to obtain SSI benefits for eligible children in out-of-home placements so that they have this income as an ongoing resource once they leave their foster arrangements.

##### ***Response to the Policy Change***

DCFS operates a health care services “hub” that uses EPSDT funding to finance comprehensive assessments of children entering foster out-of-home placements. The DCFS used its health care “hub” at Martin Luther King, Jr. County Hospital in South Central Los Angeles in response to the 1996 welfare reform. Children in foster care whose SSI eligibility was potentially affected received comprehensive health assessments in the Martin Luther King hub.

##### ***Observations of Family Impact***

The administrator suggested that DCFS has been very successful in retaining SSI benefits for children, and that there has been no impact on children in foster care in Los Angeles.

#### **3.4.5 Los Angeles County Unified School District (LAUSD)**

We interviewed an administrator with supervision responsibilities for psychological services, and a LAUSD social worker with ongoing involvement with families of children



with hearing impairments, through a special education program specifically for hearing or visually impaired young children. LAUSD is required to provide services to all children with disabilities as part of federal and state laws. The re-authorization of IDEA in 1997 and state requirements for special education are the main mandate for the public schools. Receipt of SSI does not change the schools requirement to provide equitable access to supplemental services in the regular classroom, to special classes, to related services (occupational therapy or OT, and physical therapy or PT), services for deaf and hard of hearing children, and other types of services. Most services were reported to be available to children and parents through the schools, including counseling (through the schools or through the LAUSD contract with the Department of Mental Health), PT, OT, and even therapies for children with physical problems. An important issue is making sure families know what is available, and confronting the social, personal, and cultural issues that families have that affect their access.

### ***Role in Policy Implementation***

There is no system mandate for schools to provide the educational records and information to support SSI applications and determinations. This occurs at the individual teacher and child level, and as part of special program efforts. According to the psychological services administrator, parents have more responsibility now for providing medical information, whereas earlier the SSA offices had more direct involvement in schools, sending evaluation forms, re-evaluation forms, and questionnaires, which had more of an impact on schools.

The social worker with the program for hearing impaired children reported that when parents have attended special education settings with the children, they brought up the fact that they had received letters indicating that their child may no longer be eligible for SSI, and expressed anxiety about the process. Consequently as part of the program, which provides support to parents, the program administrators have made it a point to talk about the SSI changes.

The social worker believed that not all of the forms that must be filled out for SSA are translated into the primary languages of families in Los Angeles, and thus program staff have tried to be available to help in language translation if needed by families. The social worker reported that social workers from the program, and occasionally teachers, have accompanied some parents to the SSA office to help them. Program staff has accompanied parents to a variety of different SSA offices in Los Angeles.

### ***Observations of Family Impact***

The social worker we interviewed reported that a number of child SSI beneficiaries live in families with one or both parents having undocumented immigration status, and estimated that about 50 percent of the parents of children in the program for hearing/vision impaired children are undocumented, although their children were born in the U.S. This is relevant to child SSI beneficiaries because parents often have concerns

about information provided to SSA about their immigration status and earnings, and have concerns that receiving assistance could hurt the family later when they are trying to get documentation. The social worker identified these as sources of concern during redeterminations. It was reported to us that program administrators have tried to reassure parents that their child can still receive income support without adverse immigration consequences, but that this has been difficult in view of federal changes in eligibility for some public benefits.

Another issue (not specific to children affected by the SSI childhood eligibility change) raised by the social worker we interviewed was that parents needed to establish bank accounts so that direct deposit could be made. The requirement of having a bank account meant that the parent needed identification such as California ID, which requires a Social Security Number. Most parents were able to set up bank accounts in small banks by obtaining passports from their consulate (usually Mexican) and using their child's Social Security Number.

The social worker perceived that the determinations have differentially affected children with hearing deficits, whereas fewer children who have visual impairments have been redetermined or have been denied benefits when re-evaluated. The administrator we interviewed was not aware of services parents might be purchasing with the SSI benefits, if any. Glasses and hearing aids or hearing aid batteries were suggested as specific medical items that may not be covered or easily reimbursed by Medicaid and thus may need to be purchased by families.

#### **3.4.6 Child Care Provider**

We interviewed three staff members in the Crystal Stairs, Inc. child care agency in Los Angeles. Crystal Stairs, a private nonprofit corporation, was founded in 1980 and provides child care resource and referral services, making over 7,000 referrals per year across 1,200 listed child care providers. Crystal Stairs also administers an alternative payment program (APP) to help income eligible families pay for their child care needs while at work, in school, looking for work, or in training, serving over 1,700 children. The agency also administers a child care program for children in protective services, providing subsidies and resource referrals to children at risk of abuse or neglect; the Child Protective Service Program has served 877 children in 520 families.

#### ***Role in Policy Implementation***

All licensed child care facilities are required to be capable of providing child care to children with special health care needs, as part of the Americans with Disabilities Act (ADA). Consequently there is no formal mechanism in place to identify providers who are better equipped for children with special health needs. It is not clear that parents of former SSI child beneficiaries who go back to work, and need child care, would be able to identify those providers who might have specific skill sets that better meet their child's

needs. There are provisions for an enhanced daily rate for children who require more intensive medical assistance while in childcare, however.

There is a general shortage of public funding for child care for low-income families, and this might affect families whose child loses SSI and requires child care when the parents go to work or increase their working hours.

### **3.4.7 Regional Centers for Developmental Services**

We spoke to administrators in two local Regional Centers serving different regions of the case study geographic area. The Regional Centers provide services to individuals with developmental disabilities such as autism, cerebral palsy, and other conditions related to mental retardation that originate prior to age 18. These Centers also provide services to children from birth to age 36 months who have a need for early intervention and have developmental delay, established risk for developmental delay, or high risk for developmental disabilities. One of the administrators whom we interviewed coordinates the activities of counselors who work with families, and the other is a staff. The Regional Centers do not maintain regular statistics on SSI income for their clients. An estimate of SSI beneficiaries, among one Regional Center's clients, comes from the cash-assistance-receiving families with children in the early intervention programs (age 0 to 3); about 10 to 15 percent of the 800 children in this Center were estimated by the administrator as receiving SSI.

#### ***Role in Policy Implementation***

The state agency that administers the Regional Centers across California has received the new SSI policy but to the knowledge of the administrators we spoke with, no directives or alerts have been disseminated to the Regional Centers.

For families who are Regional Center clients and lose SSI benefits, the Regional Center continues to play a coordinating and advocacy role and would help the families with cessations, and with getting the SSI income reinstated, and also accompany parents to the SSA offices if needed.

#### ***Response to the Policy Change***

No specific impact of the policy change on these centers has been perceived.

#### ***Observations of Family Impact***

In one Regional Center, counselors reported to the child coordinator on between 7 to 10 cases of child Regional Center clients whose SSI eligibility was being redetermined under the new policy. The understanding of the Regional Center staff was that all of these children's cases were under appeal, and that no children had lost benefits.

### ***Local Policy/Resource Trends***

The implementation of a county-managed Medicaid mental health services system in Los Angeles County is a significant transition underway. This transition was raised as an issue for families of child Medicaid beneficiaries with “borderline” types of mental and developmental problems. Children with “included” medical diagnoses such as ADHD are to receive mental health services related to this condition through the Medicaid mental health managed care system, administered by the County DMH. Children with “excluded” medical diagnoses such as seizure disorder, and mental retardation, are to receive needed mental health services through a reimbursement mechanism requiring a fee-for-service claim submitted directly to the State Department of Health Services. Finally, the PHPs are responsible for services and medications that are not the responsibility of the County DMH and that are not part of the mental health managed care system. According to one Regional Center administrator, this causes a significant challenge in identifying the responsible entity for children receiving medication for ADHD, as an example. County DMH will provide an initial work-up but does not provide follow-up care for such conditions in its facilities. This division of responsibility has been handled successfully on a case-by-case basis for Regional Center clients where problems have occurred, by the Medicaid PHP mental health liaisons, but there is not a systematic solution at this time.

A related issue is that behavioral problems for children with mental retardation generally are not looked at as mental health needs, which means that the mental health system is not a resource for these needs. If children enter the mental health system through the schools (the AB 3632 provision that requires needed mental health services to be provided for children in special education), their priority for service increases, but these children still rely on the County DMH system for services.

Another service system issue is the shortage of child psychiatrists in the Los Angeles area. There is a chronic shortage of services and even children who can be served within the County system can be on waiting lists for several months.

### **3.4.8 Mental Health Advocacy Services**

We interviewed two attorneys with Mental Health Advocacy Services in Los Angeles. Mental Health Advocacy Services provides legal assistance to individuals with mental illness, and also plays a general advocacy role for the mentally ill populations. This organization has played a significant advocacy and representation role for individuals affected by the eligibility changes for the drug addict and alcoholic (DA&A) population.

### ***Response to the Policy Change***

Mental Health Advocacy Services has not played a large role in the 1996 childhood disability eligibility change. The organization does a significant amount of work in special education, and the significant amount of transition planning that is involved, but income eligibility has not traditionally been a major part of this work. Most of the children who are assisted by Mental Health Advocacy Services are in out-of-home foster care

placements. These children are generally receiving federal foster care Title IV-E funds for their foster care placement, and because the Title IV-E payment is higher than the SSI payment, the organization has not played a major direct role in responding to the policy change.

### ***Observations of Family Impact***

There have been reports from the DCFS that generally they have been able to get children enrolled in SSI, but that they have difficulty getting children with mental health problems (those with behavior problems) into the SSI program.

One population that is being affected by the policy change is children reaching age 18 who have been in the foster care system. There is a major gap in attention and assistance to this group of children, although a few benefit from having a social worker who is on top of the case, or an attorney. There has been a shift at DCFS over the past 5 to 6 years towards considering the ongoing support needs for children in protective services who are emancipated from the system at age 18. The initial focus has been on children without disabilities, but DCFS now is paying more attention to children who have mental health disabilities, and turning to the Department of Mental Health for assistance. This has involved more of a focus on mental health services than it has a focus on income, however.

## **3.5 SUMMARY OF FAMILY INTERVIEWS**

We interviewed ten families in Los Angeles during the weeks of August 17 and August 24, 1998. The child SSI beneficiaries in these families were reported by their interviewed caretaker as having the following types of medical conditions when they began receiving SSI: mental retardation/learning disability; seizures and learning disability; mental retardation; emotional disorder; emotional disorder and learning disability; learning disability; hearing loss; cardiac condition; attention deficit hyperactivity disorder (ADHD); and learning disability.<sup>12</sup>

Eight of the ten families reported that they had appealed the termination of SSI benefits either at the initial termination or later in the process. One of the ten families completed a new application due to missing the appeal deadline, and one never appealed. Of the eight families who appealed, five reported that they had requested benefit continuation. Two of these five families were continuing to receive benefits at the time of the interview.

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<sup>12</sup>Caretakers were asked in the interview about medical conditions that led to the child's initial eligibility for SSI; these conditions are self-reported with no attempt made to compare the information with SSA administrative records.

### **3.5.1 Experiences with the Redetermination Process**

#### ***Understanding of the Redetermination Process***

While none of the parents expressed confusion about the welfare reform changes to SSI eligibility or about the reason for their child's eligibility redetermination several parents voiced different types of confusion about the process that unfolded.

Several parents stated that they became confused about the purpose of eligibility redetermination after they attended a child's reconsideration hearing, because they perceived that the hearings did not focus on the child's particular disability but instead on abilities that the child did have—such as basic cognitive abilities and intelligence—when the child's problem was physical. One parent was concerned that her child's benefits would be terminated after the hearing, because the questions posed by the DHO to her child were limited to how the child was doing in her school work. This was a concern to the parent because the child was in a gifted program at school at the time (the parent stated that the child is no longer in the gifted program because the stress of the class work was making the child tired and sick). This parent also reported that she was concerned about whether SSA had all of the necessary medical records because the child's physician told her that he had not been asked for any medical records during the appeals process.

One parent said that the information she had received about the eligibility redetermination process, and her child's SSI status, came from a Medi-Cal letter explaining eligibility issues, but not from any materials sent to her from SSA.

#### ***Appeals and Benefit Continuation Requests***

One parent did not appeal initially because she was hospitalized at the time, and said she had not received additional letters from SSA other than the initial letter informing her of the change in the law. Several parents stated that they had not been told that they could appeal when they were first notified that SSI benefits soon would be cut off. Several parents appealed in Spring 1998 when they were notified of their rights to appeal. None of the parents reported that they had sought legal assistance.

One parent stated that she found out that she could appeal her child's termination through "the grapevine" but that she had missed the appeal deadline and thus submitted a new application for her child. She had not heard anything about her child's case since that time and had given up after approximately one year, but had just received another SSI payment for her child the previous month. This parent did not know why she had received this check or whether any back payments would be paid.

Another parent stated that when he learned in March 1997 that he could appeal the termination, he submitted an appeal right away but was told that the appeal was filed too late; the case now is under appeal.

One parent stated that she had appealed but had not known that she could receive benefits during the appeal process until some friends told her it was possible; she has since requested benefit continuation but has not heard anything from the SSA office. Another parent did not initially appeal because he said he was discouraged from doing so by the SSA field office. He then received a letter that encouraged him to appeal, but when he submitted the appeal immediately after receiving this letter, he reported being told that he had missed the deadline. Since that time, his appeal has been accepted but he stated that his child's paperwork was lost several times. Only recently did he learn that he could have requested benefit continuation during the appeals process.

The parent of a child with a physical condition appealed in 1997 but was told in 1998 that she would have to pay back several thousand dollars for the benefits received while the case was under appeal. The parent could not pay the entire amount at one time so is currently making monthly payments. The parent reported being told that she would definitely have to pay back the full amount and did not believe that she had any alternative. This parent reported that her child's physician had said that her child would not be affected by welfare reform because it was children with other types of disabilities who would be affected.

### **3.5.2 Impact on Medicaid and Health Care Access**

#### ***Medicaid Eligibility and Enrollment***

Medicaid eligibility was reported by parents as having been terminated for two of the children. Of these children, one was a child who turned 18 in 1998 and whose case was first appealed this year; this child had lost Medicaid coverage after turning 18. The second child, who has psychiatric problems, lost Medicaid coverage after SSI benefits were ceased, but regained Medicaid coverage when the child began receiving AFDC/TANF benefits about one year later. The child's mother stated that a year elapsed while she tried to restore the child's Medicaid coverage, and that she had to take a letter from SSA to the caseworker at the DPSS office before the coverage was restored.

Several parents expressed concern that their children's Medicaid coverage would be terminated once their appeals were decided, although they did not have specific information one way or the other. The parent of a child who had had multiple surgeries was afraid that the Medicaid coverage would end if she lost her appeal. Another parent said she had been told that her child's Medicaid coverage would continue until SSA made a decision about SSI eligibility, and thus inferred that coverage would end at that time if the benefit termination was upheld.

#### ***Transitions to Prepaid Health Plans***

Parents of five of the nine children who were still enrolled in Medicaid reported that their child was enrolled in a prepaid health plan (PHP). Two of these five parents said that

they had to enroll their children in PHPs when the SSI benefits stopped. Children of three of the five parents were already enrolled in a Medicaid PHP prior to welfare reform.

### ***Access to Medical and Mental Health Services***

Three parents felt that their children's access to necessary care had been adversely affected based on Medicaid-related changes, while seven parents reported no specific problems. One parent said that while her child's medical care costs were largely covered by Medicaid, she bought large volumes of over-the-counter medication for her child that were not covered by Medicaid. The parent reported being unable to afford her medication of choice for the child due to its expense.

The other two parents pointed to the required change to PHP, pursuant to the SSI loss, as the primary reason for these access difficulties. One of the two parents who had to enroll their children in PHPs after losing SSI eligibility was distressed at this change because she was now required to obtain a referral from the health plan for her child to get psychiatric help. When her child had fee-for-service Medicaid coverage, she was able to work from a list of providers to find one who would accept Medicaid payments. She felt that she could not bring herself to working through the system to get the necessary referral, although her child's psychiatric problems were significant and he recently had started carrying a knife. This parent stated that she might try calling the Department of Mental Health to see whether they could help find services for her child. She had called the local police station when she found her child with the knife, but said that she could not get through to the police officer there because a deputy in that station had been killed several days before, but that someone might call her back. One parent said that she now had to pay for prescriptions and that she also had co-payments for some services.

Two of the children had been or were currently receiving services through the Regional Centers serving children with developmental delay/mental retardation. One of these children received periodic assessments, and her father received funds for respite care. The other child had been receiving Regional Center services (including counseling and a life skills program) before moving to the family's current address, which was served by a different Regional Center.

### **3.5.3 Socioeconomic Impact**

#### ***Total Income Levels***

Income levels did not change for the two families who requested benefit continuation and continued to receive SSI benefits during the appeal. Of the remaining families, all of whom were no longer receiving SSI benefits, total family income increased for the three parents who began working or increased their working hours after losing the SSI benefits. Family income had declined for the other five families who were not receiving continued SSI benefits.



### ***Work Participation***

In three of the ten families, the parent was working at the time that the SSI eligibility change occurred. Two parents were receiving disability income for themselves; one was receiving SSI, and one was receiving Social Security benefits. One parent was receiving unemployment. In the four remaining families, the parent was not working.

Of the three working families, one increased working hours following the loss of SSI benefits. Of the five families, in which the parent was not working at the time that SSI benefits were lost (and was not disabled or elderly), two families subsequently entered the workforce (the parent in one of these families had been only temporarily out of the workforce). In the remaining three families, the parent had not yet entered the workforce and remained completely dependent on public assistance.

Thus a total of three families had increased their working hours or taken a new job since the change in SSI eligibility. One parent who currently works 30 to 40 hours per week and would like to take on additional hours to earn more income has a child (the SSI recipient) with a medical problem. This parent now pays a friend to stay with the child after school until the parent's shift is over., in case anything happens to the child. While this parent would like to increase her work hours, she would need to pay someone to stay with her child during those hours.

One parent stated that she had attended a session on becoming a foster parent and had recently taken a licensing test. She said that monthly payments for children foster care were \$300 for a child up to 3 years, and \$400 for a child around 5 to 8 years of age. This parent felt that she was particularly patient and that this would be a good option for her, and alternatively a daycare or baby-sitting job might be possible.

### ***Use of Public Assistance***

A total of three parents had applied for or intended to apply for cash assistance to replace the lost income. One parent had added the child who lost SSI to her AFDC/TANF cash grant, and stated that it had taken a year to get the child added to the cash grant. The parent had finally taken her correspondence from SSA to the social services offices, and after this her child was added to the family cash grant. The other parent who applied to add the child to her existing cash grant for herself (and her other child) was able to add the child to this cash grant immediately. Another parent who did not currently have a family cash grant planned to apply for AFDC/TANF for the child who had lost SSI.

## **3.5.4 Caregiving and Other Child Impact**

### ***Living Arrangements***

Six of the ten parents had not moved or changed living arrangements. One parent had moved into her boyfriend's home because she could not afford rent after losing her

child's SSI benefits. One parent had gotten a new job since losing the child's SSI benefits and had moved from his mother's home into an apartment. The two other families who had moved since the SSI eligibility change occurred did not attribute their moves solely to the loss of SSI.

Another parent was having difficulty maintaining the rent for the house that her family was living in, but felt that it was important to try to work with the landlord to keep the house because her learning disabled child had been constantly teased and harassed by children and by parents in the apartment building they had lived in prior to moving to the house. Several other parents mentioned the importance of having a house, whenever possible, for this reason.

### ***Child Care***

A parent whose child had mental retardation and learning disabilities stated that she would not be able to find child care for her adolescent and younger child) if she worked; baby-sitters with the necessary patience were difficult to find. None of the parents we interviewed reported currently using or ever using non-kinship child care. All of the parents with pre-adolescent children said that they would not be comfortable with child care arrangements that were not kinship care. At least one parent stated that she was not comfortable with anyone other than herself taking care of her children, and currently is able to bring her pre-teen children to her job.

### ***Other Child Impact***

One parent had enrolled her child in a private school when she was receiving SSI, but had to enroll her in a public school for 1998-99 because the SSI benefits stopped. This parent was very concerned about her child being in a public school because the child's condition often requires trips to the emergency room. At the private school, the teachers knew and looked out for the child's needs, but the parent felt that her child would not be looked after in the public school.



## **4. SITE VISIT SUMMARY: FRESNO, CALIFORNIA**

### **4.1 INTRODUCTION**

As discussed in Section 3, California was selected as a case study site due to its high volume of affected child SSI beneficiaries, its high penetration of Medicaid managed care, and its demographic characteristics including the presence of urban counties as well as some rural counties with significant child SSI caseloads. We visited Fresno County, California during the week of October 26, 1998. We interviewed a total of nine families in addition to 14 individuals in six different agencies.

Fresno County ranks sixth among counties in California in the total number of child SSI beneficiaries, third in total IFA and maladaptive cases, third in the total cases subject to redetermination (1,157), and second in the total cases terminated with no appeal pending as of January 1998 (305). Fresno County has the highest ranking among California counties of the percent of the under 18 child population receiving SSI (1.6 percent) and in the percent of child SSI beneficiaries with IFA and/or maladaptive (22.2 percent). Fresno County ranks second in the total number of cases terminated with no appeal pending.

Because the SSA Regional Office as well as the programs and policies in the California State Department of Health and Department of Social Services apply both to Los Angeles and Fresno counties, the summaries of those interviews provided in Section 3 are not repeated in this section. Thus, in the sections that follow, we first provide a summary of interviews with staff in the DDS office and the SSA field office. Next are summaries of interviews with other local public and private agency staff, and finally the summary of the family interviews in Fresno.

### **4.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES**

#### **4.2.1 Disability Evaluation Division, California Department of Social Services**

We spoke with two DHOs, one medical liaison officer, and an administrator of the Disability Evaluation Division (DED). The DED has six teams with seven to nine analysts per team. In total there are 50.5 full time equivalent (FTE) staff working on disability evaluations. There are 120 staff in total. There are 6.5 FTE hearing officer staff.

#### ***Role in the Policy Implementation***

A major role has been compiling the policies and procedures necessary to guide the staff through the redetermination process. Staff have had to respond to a number of emergency transmittal memos that were released, to incorporate this information into the manuals. The information in the emergency transmittals often was not structured so that

the DDS had easy, clear instructions on all places within the existing manual that the new information applied. With the short time frame involved, each DDS office is performing this role (although the managers communicate regularly across the DDS). Some of the staff we interviewed indicated that this was a chronic problem with SSA policies and procedures because SSA Headquarters has less control over the policy process.

While it was helpful to get the information quickly, the staff we interviewed stated that it took significant staff time to make changes throughout the manual so that the procedures could be followed. This was necessary because line staff cannot completely depend on regulations and on piecing together the rules as they go through cases.

### ***Impact on the Agency***

**Staffing and training.** In terms of DHOs, the office gained two FTE positions during the welfare reform changes. Some staff were shifted to the hearings office during mid-year 1997 to handle the anticipated hearings.

One challenge reported by the staff we interviewed was getting the necessary medical consultative staff necessary for processing the claims. Staff reported that there is a general shortage of pediatricians and of psychologists to help with the necessary exams. This is less the case in the urban Fresno area, but is a major difficulty in the rural outlying areas. There may be no local pediatricians in some areas. It was stated in the interview that this shortage was compounded by difficulties finding providers who could fit the upcoming caseload into their schedules because many of the providers had full practices and schedules already. The staff did manage to identify an adequate provider supply and to get these providers to commit to a three month (approximately) period in mid-1997 to complete the exams. However, delays in getting the listing of affected cases meant that the DDS could not deliver the cases at the time they promised. In some cases the contracted organizations that supply many exams (“volume vendors”) brought on the necessary staff specifically for this need (such as pediatricians) but then the cases did not arrive as promised and those dedicated staff had moved on to other assignments or work.

Staff we interviewed stated that the agency chose to handle the increased caseload of eligibility evaluations pursuant to the welfare reform changes using a generalist approach. This approach to managing the caseload was adopted so that the problems that emerged could be spread across the staff; because it was important for all of the staff to know how to handle the initial claims and re-reviews. In retrospect, it would have been more efficient to delegate at least the re-reviews to a small number of staff. The case handling was very complicated and the caseload much lower than expected (about 150 cases out of an expected 500 cases). Because all staff handled these cases, it was reported to be difficult for staff to learn the procedures because they only received one or so cases per week, and did not work intensively enough on this caseload to retain the policies and procedures, which was time consuming.

**Implementation.** One implementation challenge identified by the staff we interviewed was that the Disability Quality Branch (DQB) was very rigorous in their

instructions on getting speech and language documentation. Whether or not the case already had evidence for affirmation, staff were instructed to gather the speech and language assessment information if there was any indication in the file that a speech and language problem had been identified. It took time to convey to staff that this was necessary in 100 percent of cases.

According to our interviews, in some cases the data from SSA Headquarters does not match the data reporting from the DDS. The perception by those we interviewed was that this resulted when different counts were used for certain cases. Cases that have been closed by the DDS may not appear as closed in the counts from SSA Headquarters. This can produce discrepancies in estimates of DDS caseload status.

Staff reported that it had been easier to take recipients off of SSA rolls under the changes to SSA drug addiction and alcoholism (DA&A) eligibility than it was to take child recipients off of the rolls. There was no push to speed the process and get children off of the rolls, and thus the process dragged out. There also were some parents who tried to lengthen the process by not cooperating and not attending hearings.

In terms of advocacy efforts, the DED staff indicated that there was less advocacy group involvement in Fresno specifically focusing on child SSI beneficiaries, particularly relative to the San Francisco Bay Area and Los Angeles. Staff were not aware of any concerted efforts on the part of State Department of Social Services, or Fresno County Social Services to enroll children in SSI or to specifically advocate for children's enrollment in SSI.

### ***Caseload Status***

The peak number of initial childhood disability evaluations was reported to be 134, and there currently are approximately 45 cases left to complete. The age 18 cases are more constant, with the peak this year being 23 cases at any given time. There are about 15 cases left as part of the re-reviews (from a total of about 150 that DDS had to handle). There were about 30 cases for re-review pending at any given time. The staff has perceived a drop in the incoming applications.

Reasons for higher Fresno caseloads were offered; staff felt this largely was an issue of income, with Fresno having the largest proportion of children under the poverty level across California counties. There are a number of families whose income is seasonal, and there is also a very large Asian/Pacific Islander immigrant population, particularly Hmong and Laotian, who had been refugees and rely on public assistance. The unemployment rate in some parts of the county is up to 15 to 18 percent.

### **4.2.2 SSA District Office, Fresno, California**

We interviewed two supervisors and two claims representatives in a district office in Fresno, California. The district office has 22 claims representatives and two supervisors; one is responsible for initial claims and CDRs, and redeterminations are handled by the

second supervisor. The office no longer has specialized claims representatives so for the past two years, all claims representatives (CRs) have handled both SSI post-entitlement and special claims. Title II CRs helped out with the interviews. The office got 14 temporary service representatives (SRs) to assist with the alien workload. All but two had to leave after one year, and the last two of these SRs left only several weeks ago, but the office still is dealing with the alien and the childhood caseloads. One of the SRs is helping now with the childhood caseloads, particularly sending out letters and scheduling clients for interviews. Aliens who could not provide documentation now are not supposed to be terminated, based on a recent instruction. The office had about 5600 aliens who were affected in some way by the welfare reform SSI provisions. About 250 were to be terminated but DPSS and advocacy groups have contacted the SSA office due to the impact that would be felt on the general relief program. The childhood caseload was estimated by staff to be somewhat smaller than the alien caseload, but the district office does not report out the Title 16 categories so does not have a specific count.

### ***Role in Policy Implementation***

The front end of the process (by the CR) is to contact the family, explain that the medical record needs to be updated, and explain that there is a 60 day period for appeals. The back-end is that when the case comes back, the CR inputs the information and updates the payment process. This entire process (including the appeals) can take two years due to the Office of Hearings and Appeals (OHA) backlog.

Several claims representatives we interviewed stated that the DDS expanded its staff because they anticipated receiving more continuing disability reviews and because these have not materialized yet, the DDS is “looking for work”.

### ***Agency Impact and Challenges***

**Staffing and training.** Most of the training was initiated from SSA Headquarters with videos. One problem has been that training is scheduled in certain time periods and needs to be replicated for staff who missed the first training.

The Title II CRs helped with the front-end interviews; there has been a larger number of walk-in clients needing information and assistance. All staff have to be trained when policy changes occur, because of the generalist model. Prior to the welfare reform law, when the workload was very high and before the computer programs came on line, specialization was required. There is a lot of work that the office does not have to do any longer, such as the continual updates of records that were required because the DA&A population would go on and off work, for example, and the representative payee requirement that was implemented for these clients.

One claims representative stated that now SSI has been designated “high risk” by Congress and this means that these cases are the focus and the office has to pay more attention to accuracy than in the past 5 to 6 years. Staff traditionally have not gotten to some aspects of the caseload due to the overall workload – particularly diaries – and the

office is now shifting to these, which is a drain on the staff because they need to think differently about the work they are doing, and need to make adjustments. Also, the office has been given overtime for the first 6 months of the fiscal year and told this is where the major effort is to be focused.

The staff we interviewed generally reported perceiving that the process is very politicized, and the changes have been very confusing. It is the role of the district office to explain to clients what changes are occurring and why. Because of all of the letters received and changes since the process was begun in 1997, all that clients may know is that their checks did not stop as they had been told they would. One supervisor went on radio to explain the policy changes particularly during the alien SSI eligibility implementation, especially because there were several suicides in Fresno that some said were linked to fear of losing the SSI income.

**Implementation.** An overall impact that was reported in our interviews was that the district office's professional staff no longer feels in command of all of the details. Moreover, there used to be about seven individuals at the Regional Office who were resources to the district office, and there are now about two persons who can handle the questions. Also, normally with a legislative change of this magnitude, it used to be that the instructions were greatly refined at the regional level and then sent to the district office in a format that was easy to understand and implement. Now the instructions are being received directly from SSA Headquarters without the same amount of policy review; when the district offices complain, the Regional Offices send clarifications. Staff we interviewed felt that while there may be a decline in the number of clients, the changes have increased and thus workloads have not dropped.

A tradition of the office for years has been to hold "interview days". With the alien and DA&A changes, in particular, the district office held Saturday office hours and contacted clients numerous times to implement the policy. The overriding concern for clients was how fast and complex the process has been.

This district office had high DA&A, high alien, and high childhood caseloads. In the last two years, the office also has added 10,000 square feet to the office; the SSI unit moved three times within one year. The office also established a new computer system in May 1998 and involved significant training. Thus it has been particularly difficult to get work done and there is a high level of stress among staff. There is a whole new software system for the SSI post-entitlement work.

Tracking what flags were to be used for what purposes has been a major effort. It is labor intensive for DDS if the district office mis-classifies a case. Several of the claims representatives we interviewed stated that it has been very difficult to implement these flags because the medical terminology knowledge has been somewhat limited, and this can affect the district office staff's ability to flag cases appropriately. The DDS and district office try to communicate, but the disability cases are only a proportion of all that the SSA offices do and thus the large number of case handling changes has a major effect on the district office. The district office also is getting requests from the Regional Office to get



cases to review (beginning about four months ago). Several staff told us that they thought there was concern from SSA Headquarters about getting the process right and not terminating childhood cases inconsistently particularly in California, Louisiana, New York, and Florida; the staff pointed to concerns from advocates that in Louisiana people were all losing benefits while in California fewer were being terminated.

Several of the staff we interviewed stated that while it might be naïve to wish for it, allowing those who sit across from the beneficiaries to provide input to the policy changes could save significant time and financial resources during the implementation. Some felt that thinking behind the policy changes is not always communicated, which makes it hard to communicate changes to clients; some CRs felt that they are held accountable and yet are not able to understand the rationale behind particular changes.

Staff reported that after welfare reform, there was particular concern in the Asian (particularly Hmong) community about the welfare reform law's effects. The district office conducted public relations activities including radio and TV opportunities to talk about the law, and several roundtables were held with advocacy groups. The district office sent some changes by fax to the groups, such as the good news effort, to keep the advocacy groups informed. The district office had about 140 cases in The Fall of 1998 when the information came out that the benefits would be terminated again. The advocates have been well informed and helpful in getting the information necessary for some clients to continue their eligibility. It was reported by several staff to be disconcerting for the supervisors to provide different information one month after saying something else publicly.

The alien requirements were very complex and required looking at the cases on a case-by-case basis. For the children's cases, the staff training was highly complex but the public relations aspects were handled nationally; the district office had some communication with DPSS and with the Central Valley Regional Center regarding concerns about their clients. There have not been many issues with DPSS regarding Medicaid eligibility; the perception of the field office staff we interviewed is that most families switched the child to AFDC/TANF, particularly after the first level of appeal when families chose not to fight the system. They chose to go along with the decision and just switch the child to AFDC. Changes and extensions to the benefit continuation process (with copies now going to families, the office, and DDS) also were significant over time. One staff member also noted that the disability forms changed two times in the past two years pursuant to the Government Performance Results Act (GPRA) process.

**Dedicated accounts.** Another part of the law that affected children's payments, and affected the district office more as an office than the eligibility changes (the reviews), has to do with how the office is to give money to families. Installment payments were a manual process, producing checks every 6 months, and this was burdensome. The other part is the legislative requirement to establish dedicated accounts for children. The staff we interviewed stated that this continues to be a problem and will continue to be a problem until they change it or fix it. This requires a means-tested program to give people money but tell them not to spend it, and yet there are no teeth to the provision because the

parent (not the child) is to pay back money if it becomes necessary. This provision was reported to be causing significant workload increases within the office.

The impact stemmed from the fact that the office was instructed to give beneficiaries the benefit continuation. Most had not been receiving benefits for more than six months, so when the good news letters came in, and benefit continuation was requested at the CDR, often dedicated accounts would need to be established which created more work. While the volume is not large—the office has hundreds of dedicated accounts—it is the time involved in tracking these accounts manually that creates the burden, and this is a significant amount of effort for a very small proportion of clients.

This policy also was reported by the claims representatives we interviewed to be confusing; the staff felt that the provision had been set up so that parents can only spend the money for things that are related to the child's disability, but parents are supposed to know what the money is for. The policy as described in the interviews is that parents report these expenditures in diaries, not that they get permission prior to spending the money. If the CR decides it wasn't done right, then the parent is responsible for paying it back. Staff suggested that opinions can vary significantly across CRs about what they consider appropriate. The district office has called the Regional Office for clarification and has received quite liberal guidance that has not helped guide the CRs; it is a subjective issue. The supervisors do not know how to explain the policy. The CRs felt that the instructions on the dedicated accounts were relatively clear but that each CR responded differently in interpreting the instructions for a given case.

District office staff felt that it would make more sense to place the funds in a trust fund and let the clients petition for its use. Parents are very angry that they are not given the responsibility to make the choices they think are necessary for the child. Some of the staff we interviewed noted that just like in *Zebley*, SSA will end up finding that the process has not been cost-effective and possibly that they would need to pay money back to families.

### ***Caseload Status***

The childhood re-review is completed except for the cases that are under appeal. The CRs we interviewed perceived that the ALJs were reversing a number of childhood cases.

The CRs did not perceive that the volume of new childhood applications had declined. Many referrals still are coming from schools, hospitals, and other providers.

### ***Experiences With Family Response and Impact***

Overall, staff reported that families responded well to the notices (particularly the second letter that encouraged appeals and benefit continuation) and few complaints came to the supervisors.

Supervisors had not yet perceived a significant impact for the children, largely because most of the children are still receiving SSI benefits. The office made significant efforts to get families into the office and to help them to appeal, including several letters. Staff we interviewed reported being told to encourage benefit continuation a little later in the policy implementation after the advocacy groups got involved at the national level. The hearings process could take up to two years. Those families who did not appeal despite all of these efforts are thought to be those who were just on SSI for Medicaid (and they went to get a separate Medicaid card after losing SSI) or were working and had other resources.

Most parents requested benefit continuation at the CDR review even though it is explained that they may have to pay back the payments, because they need the money. CRs were instructed not to counsel parents whether to request or not request payment continuation. There are a number of families where the whole family is receiving SSI, or some type of public assistance.

Something else that was draining on staff was that clients would call regularly to see if they would still get their check the next month, and whether any other changes had occurred. If a repayment decision is made, parents can request a waiver, and if they are receiving AFDC/TANF, then there is no way to get the overpayments repaid. The CRs make the overpayment decision, and those we talked to did not see any rationale in requiring families to use public assistance payments (i.e., AFDC/TANF) to repay past public assistance payments (i.e., SSI). Consequently few parents are being required to or are repaying the overpayments.

In terms of special populations, DPSS as the payee or foster parents tend to be well informed and no particular issues came up for these children. Children who are in foster care are receiving the higher Title IV-E payments and thus generally are not receiving SSI, and have not been significantly affected by the eligibility changes. Staff we interviewed perceived that there is highly organized advocacy and community for Asian populations. Sometimes parents who are Spanish-speaking only come to the district office without an interpreter and expect that someone at the office will be available who speaks Spanish.

The district office has a good relationship with the local Medi-Cal office and a liaison who has been there a long time and can troubleshoot the occasional problem, basically by faxing the referral to the Medi-Cal office.

#### **4.3 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES**

##### **4.3.1 Fresno County Children's Medical Services**

We interviewed an administrator of the Fresno County CCS program. The Fresno County CCS program serves children with Title V conditions, many of whom are Medicaid eligible. The agency participated in a meeting of CCS administrators in October 1997 about the eligibility changes. Following this meeting, CCS staff alerted families to the eligibility changes for informational purposes.

### ***Observations of Family Impact***

Very few children in the CCS program were thought to have been affected by the redetermination process. It is possible that one or two children have been affected by the eligibility changes, although the administrator was unaware of any specific cases. There are no children known to the program who have lost both SSI and Medicaid coverage.

### **4.3.2 Central Valley Regional Center for Developmental Services**

We interviewed an administrator at the Central Valley Regional Center. This Regional Center serves six counties (Fresno, Kings, Madera, Mariposa, Merced, and Tulare) and has a main office in Fresno and two district offices in neighboring counties. Clients served by the center have a developmental disability originating prior to age 18 due to mental retardation, cerebral palsy, epilepsy, autism, or a condition that requires treatment similar to that required for mental retardation. The Regional Center's program for "at risk" children serves children (and their families) who have or are at risk for developmental disability. The center is a point of entry for the Early Start Program for children 0 to 3 years of age.

### ***Roles for Children With Disabilities***

In addition to the therapeutic and family support services provided, the Regional Center provides advocacy for clients and provides assistance in finding and procuring other available supportive services, particularly income support programs such as SSI, rehabilitation/vocational assistance, Medi-Cal, and school district services. Typically the Regional Center helps families with the SSI application process by filing the SSI applications for them, providing medical records and documentation, and providing additional documentation as necessary and as requested as part of the disability determination process.

### ***Observations of Family Impact***

While the Regional Center expected that their clientele would be affected by the SSI changes in welfare reform, they have not seen an impact materialize. The fact that few children served by the Regional Center appear to have been affected is probably due to the severity of conditions for the population served by the Regional Center. The program managers in the Regional Center have not identified any significant new effort in SSI appeals, any children denied SSI benefits, or any problems for clientele based on the SSI aspect of the welfare reform law. The "at risk" caseload is more likely to have been affected, but no problems have been reported to administrators by case management staff.

### **4.3.3 Fresno County Office of Education**

We spoke with an administrator in the Fresno County Office of Education, Special Education Department. The Fresno County Office of Education provides special

education to a number of school districts in the county for children with multiple impairments. Most school districts operate their own special education programs.

### ***Roles for Children With Disabilities***

The Office of Education provides for 72 classes across the county for children with severe impairments, many of whom have mental retardation; other groups of children served include those who are visually or hearing impaired. Few children with SED or with learning disabilities who do not have other severe impairments are served through the office's programs.

### ***Response to the Policy Change***

While the office was opposed to children losing SSI benefits and lobbied against eligibility changes, the office has not played any role since the 1996 welfare reform law was passed. No children served by the office have been affected, to the knowledge of the administrator we interviewed, nor have teachers been significantly affected.

## **4.4 SUMMARY OF FAMILY INTERVIEWS**

We interviewed nine families in Fresno County during the week of October 26, 1998. The parents we interviewed reported that their children had the following diagnoses when they began receiving SSI: low birth weight-related problems; asthma and learning problems; attention and learning problems; low birth weight related problems and emotional disorder; attention disorder; attention and behavioral disorder; impaired motor function; learning problems; attention disorder with Tourette's syndrome and seizure disorder.

Three of the nine parents reported that they never appealed. Six of the nine families appealed the decision to terminate the child's SSI benefits either initially or following the "good news" letter. One of the six families who appealed had requested benefit continuation.

Of the nine children, one currently is receiving SSI benefits after an affirmation of eligibility, four are still in the appeals process, and four had SSI benefits terminated and have no pending appeal.

### **4.4.1 Experiences with the Redetermination Process**

#### ***Understanding of the Redetermination Process***

Most parents said that they understood the redetermination process and understood what they were expected to do to respond. Two of the nine families reported communication difficulties that affected their understanding of the redetermination process. One parent stated that she could not understand some of the questions put to her

by the DHO. This was described by the parent not as a translation barrier, but instead as a problem in understanding the terminology and the meaning of what she was told by the DHO (the “meanings” and “words”). The other one parent speaks no English and reported that frequently when she went to the SSA office, there was no Spanish language speaker or interpreter available. When this occurred, she was unable to complete the purpose of the visit. This parent also stated that she had never received Spanish-language correspondence from SSA (letters or forms), even though she (and her husband) could not speak or read English. This parent generally relied on her nine-year-old child to read and interpret correspondence. She stated in the interview that she did not believe that SSA produced letters or forms in Spanish.

### ***Appeals and Benefit Continuation Requests***

Of the six families who appealed, four reported that they had immediately appealed the initial decision to terminate benefits for the child, including one parent who was told that the appeal was one day late and thus could not be accepted. One of the four parents had requested benefit continuation. This parent appealed initially although not within the stated time limit. This parent requested benefit continuation because the family needed the income. None of the parents reported that they had sought legal assistance.

Two of the six families had not initially appealed the termination decision, but then did appeal at a later date. These two parents who appealed much later in the process stated that they did not request benefit continuation when filing their appeals because they had been told they would have to pay back the benefits if the appeal was denied, and did not feel they would be able to pay back the money. One of these two parents received a lump sum payment for the months that passed between the initial appeal and the eventual affirmation of the child’s SSI eligibility.

One of the parents who did not appeal was the one Spanish-only speaking parent. This parent reported having trouble understanding the process and stated that she did not appeal as a result. She reported that she became frustrated and had not pursued the appeal after making an initial attempt to clarify the content of the letters. (This parent also said that she was not receiving Spanish-language letters and materials from SSA.)

We interviewed one parent who stated that she had skipped a recent hearing on her child’s eligibility. This parent had received notification of an upcoming hearing (with a DHO or ALJ), to which she recalled having been encouraged to bring her child. The parent decided against pursuing the appeal because she knew a number of other families who went through the process and had not been successful in getting their child’s benefits restored.

#### **4.4.2 Impact on Medicaid and Health Care Access**

##### ***Medicaid Eligibility and Enrollment***

Two parents reported that their children lost Medicaid (Medi-Cal) benefits after the SSI payments stopped. Medi-Cal eligibility was restored for one of these children when the child was hospitalized within the past year; when the child became ill, the parent went to the welfare office and was able to enroll the child in Medi-Cal. For the other child, the parent stated that she has been hoping that the SSI income will be restored and that the Medi-Cal eligibility will be restored at that time. In the meantime, the parent had accessed migrant aid to pay for an upcoming diagnostic evaluation for the child's emotional disorder at the children's hospital.

Finally, one parent believed that her child was still enrolled in Medi-Cal but was not sure because she had not tried to access services recently for the child. This parent planned to enroll her other children (and this child if his Medi-Cal eligibility was terminated) in California's Title XXI SCHIP Healthy Families Program.

##### ***Transitions to Prepaid Health Plans***

None of the families who were interviewed stated that their child had been required to enroll in a prepaid health plan (PHP), or had become enrolled in a PHP. None of the parents expressed concern that their child might have to enroll in a PHP or that such a transition might affect the child's access to care.

##### ***Access to Medical and Mental Health Services***

Two parents reported significant problems with accessing appropriate care for their children. The parent of a child with ADD and behavior problems had tried to access psychological services; after a successful relationship with a counselor had been established, however, Medi-Cal coverage changed and would only pay for one counseling visit every six weeks. She felt that this low intensity contact would not be helpful for her child and thus did not use it. The parent was able to access psychological services through a local psychology school but felt that she and her child were not receiving help there and was only being told that she was a poor parent. An attorney who was a family friend suggested foster care as an option because the parent was unable to afford private residential care or to access publicly available care due to her status as a working parent. Now that the child was in foster care, the child was able to receive regular psychiatric services (weekly, at minimum) and had much improved access to services.

The other parent discussed the significant assistance that had been provided to her child by a school psychologist, but the difficulty she was experiencing in finding an appropriate psychiatrist outside of the school. She found one psychiatrist who would see her child but was unable to understand the psychiatrist's English when he tried to talk with her, and thus she was not going to see this psychiatrist again.

#### **4.4.3 Socioeconomic Impact**

Most families whose income declined reported that it was generally harder to cover household costs. Several families offered specific examples. One family that had never been regularly behind on household bills was now unable to pay bills in total each month, and no longer had phone service. Another parent negotiated with the landlord to lower the rent until welfare payments partially restored the lost family income. One parent was unable to afford babysitters without the SSI income, particularly as her work hours increased during swing and late shifts in response to the income loss, which caused her to sometimes leave her children alone during evening and night hours. Another parent could not afford to pay her car registration for about six months and used the bus to get to work and to get her child to therapy sessions and to doctors for care of asthma and seizures.

The parent who increased her working hours to compensate for the loss in income, and subsequently placed her child in foster care, reported that the child was no longer receiving SSI and that the parent was now paying approximately several hundred dollars monthly to support the child in foster care.

#### ***Total Income Levels***

Total family income declined in all eight families who were no longer receiving SSI benefits. One of these eight families expected that the family income might rise slightly in the next year because their welfare checks would no longer be docked to pay back welfare payments provided to the family during the father's prison term, which had ended several years earlier. The one family that experienced an increase in family income was the family that had the child's SSI restored (and eligibility ultimately affirmed) and had successfully applied for Food Stamps as well.

Four of the nine families were two-parent households. Of the five single parent families, two were receiving child support at the time of the interview and had been receiving this income since before the SSI stopped. Pursuing child support was not an option mentioned by the other three single parents.

The parent whose child's SSI benefits were restored after a favorable disability review said that she wished she could use the SSI benefits that had accrued during the appeal for the child's college fund, although she was not sure whether he would be able to attend and succeed in the local city college. Instead, she said that she had to spend the funds in a shorter period of time, and a significant portion was used to pay the mortgage on the family's new residence.

#### ***Work Participation***

In seven of the nine families there was at least one working parent prior to the changes in childhood SSI eligibility. In one of the nine families, the parent was receiving SSI for her own disability and was not working at the time. In one of the nine families, one of the two parents was working while the other parent was receiving SSI for a



disability. The remaining one family in which the parent was not already working when notification came of changes to SSI childhood disability was a parent who had been a student at the time.

Two parents of the six had increased their working hours in response to losing the SSI income. One of these parents reported that it was difficult to find a professional job because of her ethnicity. The other one parent who had been able to increase her working hours had increased her total hours worked but had ended up receiving less in total income because her new job depended on commissions. In another family, the two parents had taken more secure farm work jobs, although the income levels were comparable and there still are seasonal fluctuations in total hours worked. Thus several parents were finding it difficult to find higher paying jobs.

#### ***Use of Public Assistance***

Three of the families reported an increase in or new receipt of public assistance following the loss of the SSI income. One of these families experienced an overall increase in the total family income because the family applied for Food Stamps after the SSI benefits ceased, and then continued to receive Food Stamps when the SSI benefits were restored (as well as back payments for the missed months of SSI). One of the other two families maintained the same level of Food Stamps but increased the welfare benefit (AFDC/TANF). The other family did not receive Food Stamps but did begin to receive welfare for the child.

#### **4.4.4 Caregiving and Other Child Impact**

##### ***Living Arrangements***

Living arrangements changed in two families. The child in one family had been placed in an out-of-home foster placement within the past year. This child's parent stated that the foster care placement resulted from a combination of the financial stress placed on the household and the age of the child (who entered adolescence at this time). This parent reported that upon learning that the SSI income would be lost to the family, she began a new job with longer hours (up to 12 to 14 hours per day). This caused her to have less time with her child, who required constant supervision due to attention and behavior problems. The other one family had moved since the SSI change occurred but did not attribute the move to the loss of SSI.

##### ***Child Care***

One parent said that she did not have childcare and that this was a problem for her youngest child (the SSI recipient). Her new job required that she be "on call" during certain times, and this meant that she sometimes had to leave the child (a young teen) alone or else without supervision up to several hours at a time. One of the families used a center daycare arrangement for the two young children in the family.

### ***Overall Family Impact***

We interviewed five families with teenage children. The parents of one of the two former SSI beneficiaries who were approaching age 18 were concerned about his work and future schooling opportunities. He had tried to work with his father in farm work but was unable to work for more than an hour at a time due to his physical impairment. The parent of the other teen approaching age 18, but whose SSI benefits were continuing, also was concerned about his ability to keep a job.

One parent reported that her child's emotional disability was a major contributing factor to the dissolution of her marriage because most of her attention was devoted to her child's problems. The loss of SSI income did not contribute to this problem, however, and she continued to receive child support payments from the children's father.

Several specific issues were raised in the interviews that pertain to rural factors. Several parents stated that they relied on seasonal agricultural work to support their families, and felt that this made it difficult to receive public benefits due to the resulting income fluctuations. Limits to rural work opportunities for the children also were raised by several parents. The parents of one of the older child SSI beneficiaries stated in the interview that the child had tried to work in an agricultural job but had not been able to work for more than a short time before feeling physically unable to continue. In terms of transportation for the families living in rural areas, two of the three parents owned cars and thus did not report transportation to be a significant problem. The other parent stated that the Regional Center, which provides services to children with developmental problems, provided transportation for the child between the rural community and the location in Fresno, and thus transportation was not a barrier in terms of the child's access to medical care.



## **5. SITE VISIT SUMMARY: HARTFORD, CONNECTICUT**

### **5.1 INTRODUCTION**

Connecticut was selected as a case study site due to its sizable but smaller volume of affected child SSI beneficiaries relative to other states, its progress in welfare reform and generous Medicaid eligibility, and its status as a 209(b) state in which SSI eligibility does not automatically confer Medicaid eligibility. We visited Hartford, Connecticut during the week of September 14, 1998. We interviewed a total of eight families in addition to 13 individuals in eight different agencies.

The State of Connecticut ranks 29 among states in the total number of children under age 18 (at 797,000 in 1996). In terms of SSI participation in August 1996, Connecticut ranked 47 in the proportion of children under 18 on SSI (at 0.7 percent of children). Connecticut ranks 26 among states in the percent of child SSI beneficiaries with IFA (who represent 21.4 percent of the child caseload) and 47 among states in the percent of child SSI beneficiaries with maladaptive behavior (who represent 1.4 percent of the child caseload).

Hartford ranks first among counties in Connecticut in the total number of child SSI beneficiaries, the total IFA and maladaptive cases (356), the total cases subject to redetermination (594), and the total cases ceased with no appeal pending as of January 1998 (170). Hartford ranked fourth among counties in the percent completed of those cases subject to redetermination (ranked 4 of 66 counties)—likely due to the relative size of the caseload—and in the percent of cases terminated with no appeal pending (ranked third with 28.6 percent).

Connecticut implemented statewide TANF welfare reform in October 1996. Connecticut offers transitional child care and transitional Medicaid for longer than 12 months for welfare beneficiaries who stop receiving cash assistance.

Connecticut is one of nine 209(b) states in which SSI eligibility does not automatically confer Medicaid eligibility. Connecticut also has very generous Medicaid eligibility and covered most children up to 185 percent FPL even before the Title XXI child health insurance expansion legislation was passed in 1996. Connecticut has now expanded Medicaid eligibility for children through 18 years of age to 185 percent FPL, and offers its state-only child health insurance program, a state employee benefits package, to children 0 to 18 years up to 300 percent FPL, with a premium buy-in provision for children in families above 300 percent FPL. Cost-sharing requirements are imposed for children in families above 185 percent FPL. Child SSI beneficiaries are not specifically exempt from enrollment in PHPs.

In the sections that follow, we repeat the format established in Section 3, first summarizing the interviews with SSA office staff, then with Medicaid and other public and private agency staff, and finally with families in Hartford.

## **5.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES**

### **5.2.1 SSA Regional Office, Boston, Massachusetts**

We interviewed a childhood coordinator in the Boston Regional Office. The Boston Regional Office covers seven states including Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont. The agency has approximately 60 total staff. The Regional Office has a group of programs staff who clarify instructions to the local agencies on how to apply program policies and procedures, as well as an administrative staff. The Center for Disability Programs has several area administrators with regional responsibilities. Approximately 80 percent of the Center's work focused on supervising the DDS offices in the states, and the Center also supervises the activities of the district offices.

#### ***Role in Policy Implementation***

The regional childhood coordinator position was developed in 1996 to handle the significant policy changes in childhood disability. All Center staff have been involved in the implementation of the childhood disability changes following the welfare reform law, due to the significance of this process. Support from systems/MIS staff as well as medical policy staff are examples of the support necessary.

A significant role for the childhood coordinator has been ensuring that the policies and procedures for the new law are communicated throughout office levels. While this role has not changed for the Regional Office, the complexity of the new policies and procedures set them apart from other policy changes in recent years.

#### ***Agency Impact and Challenges***

**Staffing and training.** The overall effect of the policy implementation process, including the Top-to-Bottom review, was to improve the sophistication of the eligibility determination process. As implemented, however, the administrator we interviewed felt that the process also contributed to confusion, difficulties in maintaining quality of work (case processing and regular administrative duties), and a complex, time-consuming system that was established not for case processing improvement but for tracking and monitoring purposes. Despite these challenges, accuracy in the childhood cases was estimated at 94 percent, above the federal standard of 90.6 percent accuracy.

Although SSI is a dynamic program and changes are not unexpected, overall, the administrator reported that office staff feel stretched thin given the level of duties that are assigned. The effect of the political process and of the attention given to this policy

implementation by advocates has been to increase the sophistication of the eligibility determination process, and this has had a positive effect on the agency's work. However, this has also placed a strain on thinning agency resources, created a significant amount of confusion across agency levels, and created a perception at several agency levels that they are not able to produce the level of quality that would be possible, given time to develop and implement more refined procedures and more staff to handle the policy implementation.

Another perception stated by the administrator was that while the long-term effect of ongoing attention from advocates and others will create a more refined, sophisticated process, the short-term effect has been to remove some of the "logic" from the implementation process, which had some effect on the quality that administrators felt they were able to produce. For example, early in the implementation process there was debate about whether cases reviewed initially should be subject to redetermination when eligibility questions arose upon review that were not directly related to the new childhood disability standard. From a perspective of quality, some SSA staff wanted to "screen in" such cases to the redetermination caseload because this would enable staff to apply current SSA eligibility standards to all discovered cases. Another opportunity raised by this caseload review and proposed by SSA staff was to establish "diaries" for any suspect cases identified, which was a normal process when such cases were found in the pre-implementation process. However, according to the administrator, advocates took the position that there was a "right" for cases not directly affected by welfare reform to be "screened out" of the initial caseload review process, and that SSA should not take this caseload review process as an opportunity to review the cases for other eligibility issues. While the rationale of advocates taking this position was understood, limiting the caseload review process to eligibility issues that were technically part of the screening effort was perceived by some SSA staff as limiting the quality of their work. At the higher administrative levels, the administrator we interviewed stated that the intense oversight of the implementation process limited the extent to which administrators could use their own judgment and required that even the smallest implementation questions be called into the SSA Headquarters for comment and input.

The re-reviews that were implemented subsequent to the SSA Commissioner's Top-to-Bottom review placed a massive administrative burden on the Regional Office as well as the SSA field offices. The re-review process also has been hard to manage and budget for because it has been difficult to estimate the caseloads.

According to the administrator we interviewed, the chronology of the policy implementation was one factor contributing to the overall burden; SSA offices were not provided with implementation policies and procedures until the SSI provisions of welfare reform were fully interpreted in February 1997. At that time the SSA offices only had 6 months in which to complete the caseload review process, and schools were closing in June at which point critical school records would be inaccessible for the medical documentation process. SSA offices thus rushed to get through the caseload, not knowing that an extension in the timeline would be provided in the July 1997 BBA. Regional Offices issued a stricter memo to district offices stating that cases should be

provided to the DDS offices by May 31, 1997 so that necessary school records would be obtained. This short timeline affected subsequent administrative burdens in the following way: (1) the rush to get the cases prepared may have increased the number of “failure to cooperate” cases relative to what it would have been absent the short timeline, (2) office staff forwarded cases early and possibly without contacting families as many times as they would have liked, and (3) cases prepared by claims representatives may not have been as complete as they could have been.

**Implementation.** The implementation of the welfare reform childhood disability changes was described by the administrator we interviewed as significantly more complex than the post-*Zebley* policy implementation. The focus following the post-*Zebley* decision was on staff training to implement the new adjudicative eligibility standard. There was significant development of the supportive documentation for eligibility determination, and more work created for the case adjudicators. The focus also was on administrative decisions such as how affected children would be identified, what level of outreach and proactive procedures would be instituted, and how the standard would be modified. There also was a numeric target for the child caseload expansion of approximately a 10 percent increase.

In contrast, the adjudicative standard following the 1996 welfare reform was perceived as more straightforward and “easier” to adjudicate than the post-*Zebley* standard. The administrator we interviewed felt that there was some excitement among administrators about the greater simplicity of the new disability standard. The complexity of the implementation as perceived at the Regional Office was the implementation tracking process and the ongoing effects of the political aspects of the policy implementation.

The first issue is that re-reviews required a significant amount of complex case tracking. The administrator we interviewed indicated that the tracking burden on SSA offices was comparable to the redetermination burden, due to the workload it imposed and the ongoing confusion that was produced as staff tried to get a handle on the overlapping policies and procedures, and new priorities, handed down periodically from SSA Headquarters. There has been a significant documentation burden placed upon all SSA offices. At the administrative level, this means managing the information systems so that cases can be tracked, caseload status aggregated, and the process monitored. At the DDS and district office level, this means implementing a complex tracking process of flagging cases based on multiple, incremental changes to policies and procedures. District office claims representatives are implementing a system of manually applying case flags to identify whether cases are being re-determined, re-reviewed, re-noticed, etc. This is a complex undertaking because for example, some cases are only part of the Top-to-Bottom review caseload if they are reversed, while others are part of this caseload if they are reversed or affirmed. Collecting the data based on these systems poses another significant MIS challenge.

The Top-to-Bottom review reflected a new mindset of “leaving no stones unturned” in establishing children’s eligibility in the case review process. Prior to July 1997 the effort was to get through the caseload, and following July 1997 the effort was to give

families every opportunity to cooperate with the process. Other ongoing changes to policies and procedures had a toll at all levels. Interview forms were changed three times during the implementation period, as instructions to the DDS offices in particular continued changing.

Finally, a significant implementation challenge identified in the interview has been keeping the terminology straight. A primary job at the regional level has been getting SSA staff to use the correct language. Sometimes directives from SSA Headquarters confuse staff in the DDS or district offices because the language is not specific or clear enough. The iterations of memos can affect the case processing even though they are useful in clarifying areas of confusion.

### ***Caseload Status***

In the Boston region, only a very small number of cases have not been processed through the initial review. The Top-to-Bottom review cases are approximately 80 percent completed.

### ***Differences in Impact across States***

Several differences were noted across states in the Boston Region that have affected the impact of the policy implementation, although not directly related to the new standard itself.

Massachusetts set up a separate new unit to handle the redetermination cases due to the substantial size of the affected caseload in that state. Connecticut has traditionally had high productivity with offices and staff have received national awards, but has tended to rank lower in accuracy. In contrast, Vermont has had lower productivity traditionally but higher accuracy, and has been able to handle the redetermination implementation process without some of the difficulties that have affected surrounding states.

In terms of advocacy efforts within the states, the administrator felt that Connecticut has had a relative weaker presence of advocacy, whereas Rhode Island and Vermont have had significant involvement of advocates as the policy unfolded. Rhode Island also was more active in encouraging payees to file reconsideration appeals, and already was sending out notices and their own letter encouraging families to appeal.

Significant downsizing in the Regional Office has had an ongoing impact on office activities. It was seen by the administrator we interviewed to have had a negative effect on the quality and productivity of the office. In recent years, downsizing efforts nearly resulted in the Boston Regional Office being eliminated and subsumed in the New York region.

At the time of the interview, the Regional Office had just received a memo from the DDS division within SSA Headquarters regarding Medicaid eligibility determinations for the grandfathered group. This directive states that the DDS is the preferred



organization to redetermine Medicaid eligibility when SSI is ceased. M The initial thought voiced by the administrator we interviewed was that most likely the *Zebley* standard would be used to determine eligibility because the 1997 BBA requires that the existing standard prior to welfare reform was the standard that would be used to determine Medicaid eligibility under the grandfathered Medicaid provision.

### **5.2.2 SSA Disability Determination Services (DDS), Connecticut**

We interviewed two individuals in the Hartford area DDS, including a DHO and a medical relations officer. The DDS has approximately 150 total personnel. This includes 60 examiners (assigned to 6 separate units), 31 medical consultants, and eight DHOs (including one supervisor). The DDS and the Disability Hearings Unit (DHU) are administratively separate, although both are housed within the same agency and same building. In the DHU, there is very little interaction between physician consultative staff and the DHOs; files are not reviewed together or shared with the medical staff.

#### ***Role in Policy Implementation***

The role of the medical relations officer is to conduct outreach to local schools and to medical care providers, informing them of SSA rules and eligibility definitions. This role is an ongoing part of the medical relations position, but there has been a more significant effort since the 1996 welfare reform law, largely to assure the community that there was not going to be a “wholesale cut-off” of SSI benefits to children with disabilities.

The staff we interviewed felt that the current hearings caseload in the DDS is predominantly children, with child cases representing approximately 90 percent of the past year’s hearings for the officer we interviewed. The hearings unit grew from three to seven DHOs, and as this expansion occurred, the training of the new DHOs was geared more toward childhood eligibility issues than the traditional training had been. There was some interactive video training, and some of the more experienced DHOs attended the child specific training sessions to increase their familiarity with the childhood rules and issues.

In general, staff we interviewed estimated that the DDS purchases consultative exams for not more than about 40 percent of children. School records with historical information and historic clinic notes are more useful to document the child’s status and improvement than are one-time examinations. DHOs rarely have to request medical examinations, because these generally have been completed as part of the first two stages (prior to the hearing) unless the determination is very new. One issue raised by the DHO is that it can be difficult to construct medical records for this group of children due mostly to their families’ mobility, and due in part to their use of multiple providers. Many children move in and out of Connecticut, between Connecticut and Puerto Rico, and between Hartford and New Haven or between New York and Bridgeport, for example. This is not a frequent occurrence but is a difficult challenge when it does occur.

Another challenge to constructing the cases has been seen for children in protective custody. For example, sometimes the Department of Children's Services is unable to release information about the child for privacy reasons, or the child's name has been changed; while both DCF and SSA have similar goals, it has taken time to be able to work out these types of issues.

### ***Agency Impact and Challenges***

The most significant challenge reported for the agency is that school systems are being asked to provide volumes of information. The schools have fiscal constraints and are required to photocopy and mail records, while teachers must devote time to completing the SSA forms. For the most part, the staff we interviewed felt that schools and the teachers have cooperated with the redetermination process.

As a small state, Connecticut has only 6 major school systems. Also, the government in Connecticut is very town oriented, and thus it has been important to contact people at the town level. For the most part, relationships have been forged with the schools and with the medical providers. There also is a formal role with the public health department, as there is an effort to pick up children who cannot receive help from SSA, through the Title V Children with Special Health Needs program. The DDS sends its decisions to the Department of Public Health so that they are aware of the children who are receiving (or no longer receiving) SSI income. Occasionally there is contact between SSA and the Connecticut Medicaid program.

The re-reviews were perceived by the staff we interviewed to have had a small impact on the DDS. There have been only a few cases at the DDS level; both of the two cases that the DHO was familiar with had requested in writing that they not have another face-to-face interview.

### ***Caseload Status***

The DDS currently is through nearly all of the redetermination cases. The volume of initial cases caused a large increase in the work, and created a backlog of cases. Schedulers had to prioritize the childhood cases to get through the caseload. Medical consultants had a larger amount of cases to review, having 1300 claims to review in addition to the regular workload. There was a period of about two months where the DA&A cases overlapped with the childhood cases.

### ***Experiences With Family Response and Impact***

According to staff we interviewed, there have been fewer childhood appeals than originally expected. This may be due to parents being knowledgeable about the eligibility definition, as some parents have seen improvement in their children. Other parents appeared not to be vested in the whole process, either in the initial receipt of the SSI income or in the current process to determine eligibility for the future. Moreover, some of

the older children did not want to cooperate with the redetermination process, some in part because they did not want to be characterized as disabled.

In contrast, some parents are not knowledgeable at all about their child's status and cannot tell the DHO (a) the child's current teacher's name, (b) the name of the child's current school, (c) the location of the child's school, or all three.

According to the DHO we interviewed, parents do not always have a very sophisticated understanding of the eligibility rules, but most are knowledgeable about the process. In some cases, parents appear to have difficulty understanding that the DHO is really the decision-maker. Parents tend to ask questions at the hearing, and the DHO always begins the hearing with an explanation of why they are holding a hearing, what the changes in the law mean, and what the history of SSI for children has been. The DHOs spend some time talking with the child directly, and explaining what "disability" means and that it is not a bad word.

Most parents (estimated at about 75 percent) who appeal a termination decision have requested benefit continuation. This is most likely because of what the SSI check means to the household and the overall family budget. Many parents describe during the hearing exactly how they use the SSI income.

Few parents were accompanied by attorneys when they attended the child's hearing. Attorneys generally were helpful to the process because they were able to procure necessary records with a short turn-around and could supply information for the medical redetermination process. F According to one staff member we interviewed, for the DA&A cases, the Department of Public Social Services had contracted with a law firm to handle these cases, after screening through the cases for those that had relatively high versus relatively low reversibility. The purpose was to help move the state caseload to the federal caseload, where possible.

The DHO's perspective was that claimants generally come away from the hearing feeling comfortable and satisfied with the process, even when the case is discontinued. Parents often provide positive feedback to the DHO, and appreciate the face-to-face time that they receive. Another response from some parents, which has occurred as the welfare-to-work reforms progress in Connecticut, has been to ask the DHO about the officer got that job, what training was necessary, what college was attended, and so on. These parents express curiosity about how to go about getting a job.

Staff reported that initially there was tremendous concern within the community about children losing their Medicaid benefits; however, this concern dissipated when it was realized that in Connecticut, Medicaid is not directly linked to SSI status. Children's eligibility for Connecticut's "Husky" child health insurance program ensures that children are eligible for Medicaid even if they lose SSI.

According to the medical relations officer we interviewed, some medical providers in the community appear to be more satisfied with the SSI eligibility changes in welfare

reform because in the past, they had felt pressure to diagnose their patients with disabilities so that SSI eligibility could be met.

Experience has shown that children often attend/are brought to an initial clinic visit, but that the best intentions are not followed up and the subsequent visits do not occur. Missed medical appointments are a frequent occurrence.

### ***Local Policy/Resource Trends***

According to some of the staff we interviewed, the community perception of the Medicaid managed care implementation has been that more services will be available to children. However, managed care arrangements can limit children's access to services and this can cause problems. Parents need to wait for services and need to work through a PHP's system to get particular services, and the staff we interviewed felt that this takes both education and time.

### **5.2.3 SSA District Office, Hartford, Connecticut**

We interviewed two administrators in the district office, and two claims representatives. The district office that we visited has approximately 52 employees. This office specializes its workers and separates those who work on SSI from those who handle Social Security cases. There are about 15 or 16 claims representatives who work on SSI cases; they handle new claims appeals, reviews, waivers, complex overpayment issues, and cases where earnings are "scrambled" (such as when two Social Security Numbers appear). There also are service representatives who provide support to the claims representatives on the cases; they handle office reception, general income issues, payee choice, direct deposit, verification of income/benefits, and use an alphabetical breakdown for post-entitlement work on the office's caseload. The claims representatives and the service representatives interact daily for coordination purposes.

### ***Role in Policy Implementation***

Because of the large volume of childhood cases that needed to be redetermined, the entire staff was trained on how to handle the childhood cases. This was in part because all staff answer the phone and talk to beneficiaries. The training was tailored to focus on what the claims representatives should expect with the childhood cases, such as the public school IEP forms, and information from schools, therapy, speech therapists, and so on.

The representative payees came in for in-person interviews or else completed the forms by telephone; the medical and other forms were not completed by the families by themselves, as the manual advises staff not to use "self-help" packages if there are language barriers or a lack of education. When parents send in their own versions of the forms, the staff compare the parent's version with the forms that staff have completed, and this cross-check generally finds things that the parent has left off of the form.

### ***Agency Impact and Challenges***

A significant challenge to the district office was distinguishing between cases in appeal and the re-review cases, and keeping track of the status of the cases. As the CDR process moved along, there was special confusion because of the volume of different flags that needed to be used to code the status of a case. There was good communication between the DDS and the district office, easing the process. If the DDS staff had confusion about what forms the district office had sent, the staff would call to resolve the problem so that cases were not being sent back and forth and causing delays.

One difficulty for the office that was reported in the interview was that beneficiaries were receiving letters about their cases and asking questions of the office staff. The staff frequently needed to see the letter itself to understand what specific letter the payee had received.

Other welfare reform changes were seen to be affecting the SSA office indirectly. Changes in the income deeming process, making it more complicated and time-consuming, has resulted in the claims representatives taking on more of an eligibility worker role. SSA offices have always used computer matching but in the last two years, there has been significantly more computer matching for things such as bank accounts, pensions, earnings, interest payments, unemployment payments, etc.

**Dedicated accounts.** Dedicated accounts were raised in the interviews as a major challenge to the office. This requires that any time more than 6 months of benefits are due to paid in a lump sum to a child, a dedicated account must be established for the child and tapped by the payee only for medical and educational purposes. This has occurred for a significant number of families because of the continuations of many childhood cases. Some of the staff we interviewed felt that this policy was in response to the large amounts of funds that were dispersed to payees in the post-*Zebley* period with no restrictions in the use of the funds, which could reach \$30,000.

The impact on the agency was partly the negative public relations that it caused, because many payees thought that they would get the regular benefit when they responded to the March 1997 “good news” letter, and instead they got a dedicated account. The other impact of this rule has been in the time it takes for staff to implement the procedures that go along with it. Staff must review the dedicated accounts to determine whether the payee has misapplied any of the funds (as distinguished from misuse, which would require identification of a different payee) and thus would have to pay back any of the expended funds. Staff expressed concern that the process of getting parents to pay back any misapplied funds would not go well and would constitute a significant workload imposition. The two claims representative we spoke to stated that they each had one case in which the parent had used the dedicated account correctly.

### ***Caseload Status***

The staff we talked to said that only eight childhood cases in their total caseload have not yet been found. This district office is using the Manual Development Worksheet (MDW) mechanism to try to find these cases. This electronic field in the SSA database enables comments and flags to be attached to the national database, so that these cases can be referred to the district office in case the families come to a SSA office elsewhere. This mechanism had been available for a while but had not been used systematically in the office; office staff first used it for the re-reviews from the Top-to-Bottom review, and now the MDW is used for many purposes including tracking particular cases.

### ***Experiences With Family Response and Impact***

According to the staff, many families responded to the initial letter they were sent, which stated that there was a new law affecting the definition of childhood disability, even though the letter stated that their child's case would be reviewed in the future and that they should not contact the SSA district office at this time. Following the "good news" letter, almost all of the payees came to the office and were aware of what they needed to do. Office staff tried to contact the payees who did not contact the office; all payees took the letters seriously.

Almost all payees appealed when the cases were ceased, and most of these payees also requested benefit continuation. The exceptions were largely parents who were working, and payees who had been receiving only a small amount of SSI income, in contrast to those payees who were receiving closer to the maximum SSI amount. Staff believed that parents who did not appeal generally thought their child would not be approved if they appealed, and that benefits paid during that time would need to be paid back. District office staff stated that the first protocol used to describe these provisions to families emphasized the pay-back provision, while the second protocol that is now used (implemented some time earlier in the year, around the time that the good news letter was released) is much softer in tone. Payees must request waivers from the service representatives; the claims representatives did not know whether this was a problem. Currently, most payees who requested benefit continuation are still waiting to find out the outcome of their case. The supervisor told us that as a claims representative she had seen only one garnishment, but that she has seen 50 in the past few years.

Staff reported that it is not clear how many payees will have to pay back benefits. Most payees who have requested benefit continuation during an appeal are still waiting for their hearings to be completed.

There were very few "failure to cooperate" cases. Office staff made an effort to find people who did not call back, and used "skip-tracing" to find people who had not responded. This included contacting other agency case workers to find people, such as the State Administered General Assistance program staff.

One special population identified by those we interviewed was children in protective services. There were about 60 cases that were categorized as failure to cooperate in June, although this number was significantly reduced by July. This occurred because of the difficulty of getting all of the paperwork on a timely basis from the Department of Children's Services (DCF). The SSA office worked hard to make this process move more smoothly to ensure that benefits were not ceased. The district office send DCF lists on a periodic basis to facilitate the tracking of these cases. In addition, the SSA office prepared a template letter that DCF could use to request "good cause" provisions for the cases with delayed paperwork because this was the easiest way to keep the children in foster care receiving SSI. Office staff said that DCF does a good job of completing the forms and that periodic meetings between DCF and SSA office staff were helpful in ensuring that the process went more smoothly.

Office staff we interviewed stated that they sometimes converted new applications of families whose appeal time had expired and benefits terminated, to requests for appeal. This was done because if a new claim is started, SSA will not provide retroactive benefits. There was an internal decision to represent the case as an appeal and to apply "good cause" for ceased cases due to expired time limits.

The trend since welfare reform was implemented is that more of the parents in childhood SSI cases have some type of work and have bank accounts. Both the new applicants and those whose children's cases are being reviewed are working poor, many of whom previously had been receiving AFDC/TANF. Staff also noted that many more families are receiving child support.

The staff also stated that there is another way that families may be affected. For families who received welfare, SSA did not count family income (wages) in calculating their SSI benefit when the income already had been counted for purposes of the welfare benefit calculation. However, when families no longer receive welfare for other members of the family - which happens when families' welfare benefits are terminated due to time limits, for example - their income is then counted for the SSI benefit. The result of this income accounting is that families who are affected by welfare reform time limits or other policies are "hit twice" because not only do their welfare benefits end, but also their SSI payments decline when the income is counted (this is true for families receiving SSI as well as those in appeal and requesting benefit continuation). Many families reached their time limits (21 months on assistance) in March-April 1998. Families often do not realize that they need to report that their state public assistance has ended, and this can result in overpayments (of \$10-\$20 per month) that families must pay back. The state does not inform SSA when SSI recipients/payees are cut off from state aid and thus SSA only discovers these overpayments in re-reviews of cases.

The claims representatives felt that more families were receiving child support than in the past. They felt that parents were looking for other ways to replace the lost income. Staff perceives that more people are reporting working income, such as from "working under the table" or working for rent, than has occurred in the past.

The claims representatives reported that families rarely ask them for referrals for medical services or needs, with one CR stating that she recalled receiving requests only two or three times.

### **5.3 SUMMARY OF INTERVIEW WITH MEDICAID AGENCY**

We interviewed an administrator of the State of Connecticut's Medicaid program in the Department of Public Social Services. Connecticut is a 209(b) state that does not confer automatic Medicaid eligibility to SSI recipients. Medicaid coverage for low-income children extends to children with family income up to 185 percent of the FPL under the federal "Ribicoff" provision, which confers Medicaid eligibility to children irrespective of their public income assistance status. Children receiving SSI are most commonly in a Ribicoff assistance group.

#### ***Response to the Policy Implementation***

Because Connecticut is a 209(b) state that does not link Medicaid eligibility to SSI status, the Medicaid program did not have a significant role to play in the implementation of welfare reform as it pertains to SSI.

The only response of the Medicaid program was to track the transition of children who lost SSI as their families moved to the state's TANF program. This is an effort that is still in process. Because many families began moving to the TANF rolls as SSI income was lost, the State made some efforts to make sure that appeals were filed. Connecticut's DPSS (not the Medicaid program specifically) has sent notices to clients informing them about their Medicaid eligibility, using listings of names provided by SSA.

The Medicaid program also is in contact with the Disability Determination Services (DDS), which is another agency within the Connecticut State government, about the case review processes underway.

#### ***Impact on Children's Medicaid Enrollment***

The administrator we interviewed did not know of any instances in which children lost Medicaid as a result of losing SSI in the eligibility redetermination process. Most children would have remained in the Ribicoff eligibility group or would have been switched to a TANF (cash assistance) linked eligibility group.

Child SSI beneficiaries who are affected by the age-18 redetermination policy could experience Medicaid eligibility changes, however. Connecticut extends Medicaid coverage up to 185 percent of the FPL through age 18. Individuals ages 18, 19, and 20 could receive Medicaid through the Ribicoff group or alternatively, as disabled adults. If an individual is receiving Medicaid in an adult, disabled eligibility group, then parent income and resources do not count in determining the individual's Medicaid eligibility. However, for individuals in this age group who are in the Ribicoff eligibility group, parent



income and resources are counted in their eligibility determination and thus some 19 and 20 year olds could potentially not qualify.

### ***Impact on Children's Access to Services***

In Connecticut, enrollment in PHPs is mandatory for most child Medicaid beneficiaries, with the exception of children who are institutionalized or in long term care. SSI recipient status does not confer any exemption from PHP enrollment for children in the community.

## **5.4 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES**

### **5.4.1 Department of Children's Services, State of Connecticut, Hartford**

We interviewed two Department of Children's Services (DCF) staff in the Revenue Enhancement Division with administrative responsibility for SSI and for other revenue sources for children in protective custody. The DCF administers protective services and child welfare programs. The agency had approximately 80 children in protective custody who were affected by the 1996 welfare reform law and whose SSI eligibility was redetermined. The DCF typically tracks all children in protective custody who are receiving income benefits.

### ***Role for Children With Disabilities***

In general, the staff we interviewed felt that DCF has maximized agency revenue by maintaining children's SSI eligibility where possible, but by suspending the benefit payments to the child because the alternative payment source for many children, federal Title IV-E foster care funds, provides higher monthly payments for children in out-of-home placement relative to SSI monthly payments. One staff member explained that thus DCF becomes the SSI representative payee but suspends SSI payments for up to 11 months per year (for children remaining in the system for that period of time) and receives a SSI payment rather than a IV-E payment for the 12th month so that SSI eligibility is not terminated. The Revenue Enhancement Division developed a special tracking system for children receiving SSI who were affected by the redetermination process.

Depending on the caseload, DCF may or may not get around to applying for SSI on behalf of children who were not receiving SSI at the time they entered protective custody. However, the staff we interviewed felt that DCF is very attentive to the paperwork necessary to change the representative payee from the family to DCF, and this generally occurs without delay (i.e., within a month).

Social workers arrange for the medical care of children in protective custody. The administrators we interviewed stated that needed medical care is provided whether or not a payment source (e.g., Medicaid) has been identified.

### ***Response to Policy Change***

According to the staff we interviewed, social workers did not always appeal children's cases if benefits were ceased. For some children, social workers decided that it was not worthwhile to appeal because the disability was not at a severity level that justified the appeal effort. While the social worker makes the decision of whether the appeal to accept the termination, the agency automatically requests benefit continuation if the social worker does decide to appeal. In the past, the administrator we interviewed thought that there have been times when DCF has had to pay back SSA for overpayments.

The change in SSI eligibility in the 1996 welfare reform law increased the workload of DCF staff. This was largely due to increased need for completing forms, procuring medical exams, and putting together supportive materials. The supervisor we interviewed estimated that the policy change had imposed staff costs on the agency of about 20 staff hours per redetermined child.

SSI payments do offset the costs of out-of-home care for children in protective custody, although the costs of care are always higher than these payments. About 50 percent of children in DCF are reimbursable by the state. The maximum SSI benefit does not change when the representative payee changes.

The SSA district office notified DCF of the policy change and worked together with DCF through the redetermination process.

### ***Observations of Family Impact***

The administrators we interviewed felt that some children in DCF protective custody had lost SSI benefits due to the lag time between the arrival of the necessary forms from SSA and the completion and submission of the documentation. This is because social workers are very busy and have a significant amount of paperwork requirements.

There is no financial or other impact on children when they are in protective custody. The child's placement and service provision are made independent of their financial resources. All children have \$600 in their own account when they leave protective services.

There may also have been a financial impact on the families of children who left protective custody, although DCF does not have a way of tracking this impact. Children who leave protective custody may not have had all of the necessary forms submitted on their behalf, once DCF was no longer involved.

No impact on children's Medicaid coverage has been seen in DCF due to the policy change. Medicaid eligibility determinations are completed within DCF, rather than completed by Department of Social Services social workers, for children in protective custody. Because Medicaid eligibility levels in Connecticut are generous, at 185 percent of the FPL prior to the Child Health Insurance Expansion and up to 300 percent of the

FPL following SCHIP (through the Husky program), eligibility was not expected to be an ongoing problem. However, the administrators stated that children who left DCF could have had interruptions in coverage unknown to DCF.

#### **5.4.2 New Haven Legal Assistance (New Haven, Connecticut)**

We interviewed an attorney in the benefits division of New Haven Legal Assistance. New Haven Legal Assistance provides legal assistance as an office providing assistance to families who meet certain poverty guidelines. The benefits unit works on Social Security cases, and recently many of those cases have been childhood cases because there were many children whose benefits were terminated, and a number of children for whom applications had been submitted but not fully processed when the welfare reform law was passed. The attorneys help families by reviewing the correspondence they have received, by reviewing the files, and in some cases by representing them. Most involvement has been with individual cases, although there has been some presentation activity and some mailings by the agency. When this agency stopped taking federal legal services corporation funds, there became a new statewide organization called Statewide Legal Services that became a conduit for clients throughout the state. With an 800 number, Statewide review the cases as they come in, responds to specific questions, and distributes the informational and educational materials. Cases that required legal representation would be referred to one of the three regional offices (New Haven; Greater Hartford Legal Assistance; and Connecticut Legal Services).

#### ***Role in Policy Implementation***

The changes were very significant; people were just becoming familiar with the post-*Zebley* rules and the terminology and then were faced with completely different rules.

The attorneys generally have advised families to go through the reconsideration and to turn to the attorneys if there is a cessation.

The attorney did not know how many families received legal representation, and how many went through the hearings themselves. Often families came to the legal services program following their hearing with a DDS DHO, with the detailed information that had been compiled as part of this process. This was something that had not happened before, and made the attorneys question whether they wanted to become involved earlier in the process. They had generally advised families to apply and go through the reconsideration, and to provide some advice but not provide legal representation until the need for a hearing (an ALJ level hearing) had arisen (unless the parent was not really able to function). There are too few attorneys to become involved in the cases from the very beginning of the process.

### ***Observations of Family Impact***

The attorney we interviewed felt that the judges had been very decent about the cases they handled, not always questioning the child, and medical experts have attended all of the ALJ hearings that the attorney had handled. Approximately 30 cases had advanced to the ALJ hearing level. A finding that affirmed an earlier cessation had a positive side; no disability was found based on the medical evidence. No cases had yet been taken from the ALJ to the final Appeals Council level.

In many cases, families received a flurry of mailings but did not completely understand their rights. This sometimes caused delayed responses. . Due to the confusion at the beginning about what was happening with the cases, it was reported in the interview to be very important that SSA allowed appeals to be filed after an extended period, into January 1998, which allowed families to request hearings and retroactive benefits back to the time that they had been terminated.

According to the attorney we interviewed, family responses also depended on whether the family had access to other income sources/benefit programs when the SSI stopped. Some families, however, had access to those programs but were not aware of them and were not taking advantage of them. For these families, the consequences of losing benefits thus were much more significant.

Some families were subjected to significant delays in the processing of their new applications; several clients had filed applications in late 1995 or in early 1996, and had not received a determination by August 1996 when the hearings were stopped until early 1997. This often required the physicians to provide more information for the cases.

The attorney we interviewed felt that families did not have a good handle on the hearings process and the mechanics of those hearings, and did not have a good understanding that the hearing would occur and how to go through it. The attorney we interviewed was not aware of any problems with Medicaid coverage. There were no systemic problems that the attorney could think of or that had been discussed. In some cases, there was an oversight that could be quickly corrected because the child was clearly eligible, and in some cases the families had not done what was necessary to have the Medicaid continued through another eligibility mechanism.

### ***Local Policy/Resource Trends***

The welfare reform changes to the public assistance program are having a significant impact. Families that do not pay close attention to the requirements of the program can find themselves completely out of the public assistance program, and out of medical coverage as well. Some parents can be considered exempt from the time limits and from the work requirements, and several clients have tried to do this because of the need for home or after-school care for the child. There is not the understanding of this that there probably should be. For example, the social services caseworker could determine whether the parent is exempt right away, by asking whether a child in the household is receiving

SSI. There is little sense of how it is working or not working because the changes have been ongoing.

Another aspect of the welfare reform law that has affected families is the dedicated savings accounts policy. The attorney has explained to clients the need to put aside the money that has been placed in the accounts for the child. One attorney in Hartford had reported that one of their clients had received a letter stating that their money had been spent wrongly. It was felt that there are significant restrictions on how the retroactive sums can be spent. For some children, the money may remain there and not be able to be spent. It is not completely clear what kinds of things are considered permissible. Clients have been advised to talk to their field office worker to determine whether the expense is allowable, because otherwise the parent will be liable for paying the money back. For clients who don't have English as the first language this process can be more difficult. According to the attorney we spoke with, a district office had asked the attorney to help with her client, who had not set up a bank account before and was having trouble with this rule. These restrictions are very new, and the attorney felt that the letter to families from Social Security does not say very much, so it may not be clear to families what expenses are allowable. It is too early to know whether appropriate uses of the money are not being made and whether inappropriate uses of the funds are occurring.

## **5.5 SUMMARY OF FAMILY INTERVIEWS**

We interviewed eight families in the Hartford area during the week of September 14, 1998. Parents of these children reported that their children had had the following diagnoses: learning disability/ADHD/asthma; physical disability; developmental/learning disability/asthma; cleft palate/ADHD/impulsive/learning problem; psychiatric problem; hyperactivity; developmental/learning disability/speech; growth problem/learning problem; learning disability/psychiatric problem.

Five families reported that they had appealed the initial decision to terminate benefits for the child. Three of the five families who appealed had requested benefit continuation, and were continuing to receive benefits during the appeal. Two of the eight families had not appealed the cessation decision. One of the eight families had not received cessation information and thought that the child (currently institutionalized) had not been affected by the eligibility change and instead that SSI payments were temporarily suspended during the institutionalization.

### **5.5.1 Experiences with the Redetermination Process**

#### ***Understanding of the Redetermination Process***

Most parents said that they understood that eligibility had changed and the child's status would thus be re-evaluated. Most families we interviewed said that they understood the initial letters that they received from SSA, in terms of their appeal options and what steps they needed to take to appeal the decision. Nearly all parents said that

once the process began, however, they did not understand what was happening. Parents generally reported that they were confused at the way the process had unfolded over the course of a year or so. Six families reported that the process was confusing to them, particularly the question of how the Medicaid enrollment would be handled. Several parents stated that they did not know the current status of their child's case, but that they believed that the appeal was still in process. They had not heard of any resolution of the case for a long period of time, however.

### ***Appeals and Benefit Continuation Requests***

One of the five parents who appealed stated that she appealed the initial cessation due to her participation in the school's evaluation/review of the child's learning abilities, provision of necessary papers about the child's functional status by the school, and encouragement from the child's doctor. Two other parents who appealed stated that the children continued to have the same problems that they had had prior to the new law, and thus they believed that the benefits might be restored following an appeal. None of the parents reported that they had sought legal assistance.

One of the two parents who did not appeal initially but did eventually appeal the cessation decided to take this option after receiving the "good news" letter in Spring 1998. The other one parent who eventually appealed said that she did not appeal the initial cessation because the family had moved outside of the city and did not receive the notification letters; this family has since filed an appeal. While this family believed they had requested benefit continuation when they appealed the child's case (sometime in 1998), several months later they had not yet seen any deposits in the bank account.

Three of the five families who appealed had requested benefit continuation during the appeal. One of these three families reported that they were currently having to pay back the SSI benefits received during the appeal period.

One parent who appealed but did not request benefit continuation reported that she had been significantly affected by the dedicated accounts policy. The parent stated that she had not requested that the child's benefits be continued during the appeal, because she did not want to have to pay the money back. The child was found to be eligible for SSI following the hearing (referred to as the "court"). However, the total SSI payments that accrued during that time, which amounted to several thousand dollars, were placed in a bank account and subject to spending restrictions that the parent stated would not have applied if SSI income had been paid on a monthly basis. The parent said that she did not know this would result if she declined to request benefit continuation. The parent was told that she needed approval from the SSA office to spend the money, but did not understand how the money could be spent. She stated that she did not think that any purposes would be approved, and that the SSA person she met with did not want to see her receipts or hear about why she purchased the things she did. This parent also said that the welfare office wanted some "backpay" for the nine month period that she had received cash assistance for the child (which the parent estimated had amounted to about \$100 per month during the nine month appeal).

In one family, the child had been institutionalized in a juvenile facility for several months, and had spent some time in an institution for an emotional disability prior to that. The family believed that the SSI benefits had been terminated for the child not because the child's disability no longer met the SSI childhood disability definition, but instead because the child was in an out-of-home placement. The family believed that SSI benefits would be restored once the child returned home in the next month.

No language or translation issues with SSA offices or letters were identified by the three non-English speaking families (all Spanish speaking) whom we interviewed. The Spanish-only speaking families that were interviewed said that translators were generally available at the SSA field office.

### **5.5.2 Impact on Medicaid and Health Care Access**

#### ***Medicaid Eligibility and Enrollment***

The child's Medicaid eligibility was reported to have been terminated in two of the families. In one of these families, the child's Medicaid eligibility was terminated at the same time that SSI benefits stopped. This child did not have Medicaid coverage for 18 months but benefits were restored in August 1998. The parent of this child said the social worker in social services told the parent that she did not understand why the Medicaid benefits had stopped.

The other one of these families reported being referred back between the Social Services agency and the SSA offices to have the child's Medicaid continued/restored. The parent reported that the SSA office told the family that the social services office would take care of the child's Medicaid eligibility. The Social Services agency told the parent that SSA would have to handle the child's Medicaid eligibility because the child's case was being appealed. The family had not pursued the eligibility issue after being referred back and forth between agencies. Several months later, after reaching age 18, the child applied for emergency assistance (a program that provides short-term cash assistance—(about \$300 per month)—for three months). The family did not know that the child could receive Medicaid through this cash assistance; in the second month of receiving this income, they realized that the child had a Medicaid card through this program. When they tried to use the card, however, they were told by the health care provider that the card was "invalid".

#### ***Transitions to Prepaid Health Plans***

Among the six families who reported that they child's Medicaid eligibility was not interrupted, one family said that they had received a letter stating that Medicaid for all family members would end in the year 2000. One family stated that the child was switched to a PHP after SSI benefits stopped.

### ***Access to Medical and Mental Health Services***

Three of the eight families reported specific access to health care issues following SSI loss. One had a physical disability and emotional problems, and two had mental health problems. One of the three children had a physical disability and emotional problems, had been told during an emergency department visit that something could be done for his physical problem but having lost Medicaid coverage, there was no insurance to pay for it. This child was continuing to see a psychologist at a local high school where the child had been enrolled before dropping out of school.

One parent said that her child was able to see a counselor at a local clinic that she believed SSI (not Medicaid) paid for and that she had been referred to this clinic by a physician that SSA sent her to (in Spring 1996). The child had seen the counselor twice each week for 18 months before the SSI benefits stopped at the beginning of 1998.

### **5.5.3 Socioeconomic Impact**

#### ***Total Income Levels***

Of the six families whose child's SSI benefits had stopped (either terminated or appealed with no benefit continuation), total family income had declined for four families. In the other two of the six families, total income had increased since the SSI benefits stopped. In one case, income increased because the parent applied for public cash assistance and food stamps for the first time and was receiving more from these sources based on the family unit than had been received from the monthly SSI amount. In another case, the family was now receiving Social Security payments due to the death of the child's father, and this increased total family income.

One of the six single parents was continuing to receive child support for the child. None of the other five single parents reported child support as a source of family income.

#### ***Work Participation***

Parents in six of the families reported that they were working at the time of the interview. Three of the six parents had been working prior to welfare reform, and the other three parents got jobs following the welfare reform changes in Connecticut (both the SSI change and the implementation of time limits for cash assistance).

The two parents who were not working included an elderly guardian and a parent who was currently exempt from the welfare reform time limits. The child's guardian in one of these families was an older relative who receives Social Security and does not work. The other parent had been in special education as a child and is not able to read. She had participated in job training in 1997 and briefly held two sequential jobs, but had never worked and found the jobs to be very stressful. She came home crying every day and could not cope with her supervisors when they had an "attitude". Her doctor currently was helping her apply for SSI for herself. This parent had received one six



month extension of welfare benefits due to her health problems, and was going to request another extension in the next meeting with the social services case worker.

One parent was having difficulty keeping her job and meeting her child's needs. This parent needed to be available when problems occurred at school, but her employer did not always allow her to receive phone calls from the school or to leave work for school problems or a child's therapy appointments.

### ***Use of Public Assistance***

Of the three families that reported they were not receiving other cash assistance at the time that the child's SSI benefits were lost, one family had since sought and begun receiving cash assistance for the family. Of the four families who were receiving cash assistance at the time that the SSI income was lost, the cash assistance payment had increased for one family and had stayed the same for two of the families. Cash assistance had ended for the fourth family due to time limits.

The 18 year old former SSI beneficiary in one of the families had received three months of emergency assistance about the same time that the family appealed the cessation of benefits. Eligibility for these emergency benefits had expired since this time, and the family was not aware of any other public assistance for which the 18 year old might qualify.

One of the parents currently receiving public assistance had worked for two months in the past year, and received a child care subsidy for her two children during that time. The state paid her family member approximately \$300 per month (estimated as \$3 per hour per child) to take care of her children, but according to the parent we interviewed, this income was given back to the mother for support of her family).

## **5.5.4 Caretaking and Other Child Impact**

### ***Living Arrangements***

Two families identified changes to living arrangements that had occurred following the loss in SSI income. One parent stated that the family had received federal housing assistance in the past year, some time after the SSI benefits were terminated. In the other one of the two families, the child had been living for a short time in a nearby town when the SSI changes occurred, and had recently moved back to Hartford. No child custody changes were reported to have occurred among the families.

### ***Child Care***

No specific child care concerns were mentioned by the families. Those families who used child care for their children stated that they relied on family care.

***Other Child Impact***

In the three families with teen children who were interviewed, one former SSI beneficiary did not have specific plans in terms of work and schooling. This child had worked for several days but “couldn’t keep up” due to the physical disability. This child had enrolled in an adult day school but stopped going after his family could no longer drive him there. This 18-year-old reported that teachers gave him a hard time in class in terms of accommodating his disability. Before leaving high school, the child had taken part in an anger management program that tried to help with job placement, but no job was found.

The parent of another teen had no specific concerns for the teen's future job prospects. The other parent with a teen did not know what job prospects the teen, who was currently institutionalized in a juvenile facility, might have.



## **6. SITE VISIT SUMMARY: NEW ORLEANS, LOUISIANA**

### **6.1 INTRODUCTION**

Louisiana was selected as a case study site due to its high volume of affected child SSI beneficiaries, and its low initial continuation rate for child SSI redeterminations. We visited Louisiana during the week of October 5, 1998. We interviewed a total of nine families in addition to fourteen individuals in six different agencies.

Louisiana ranks 21 among states in the total number of children under age 18. In terms of SSI participation in August 1996, however, Louisiana ranked ninth among states in the total number of children on SSI and second in the proportion of children on SSI (at 3.1 percent). Louisiana ranks 11 among states in the percent of child SSI beneficiaries with IFA (27.2 percent of the child caseload) and 44 among states in the percent of child SSI recipients with maladaptive behavior (only 2.6 percent of the child caseload).

Orleans parish (which includes New Orleans) ranks highest among the parishes in the total number of child SSI beneficiaries, total IFA and maladaptive cases, total cases subject to redetermination (2,779), and the total cases terminated with no appeal pending as of January 1998 (817). Orleans parish ranked lower than many other parishes in the percent completed of those cases subject to redetermination (ranked 29 of 130 parishes)—likely due to the large caseload size. Orleans parish also ranked low among parishes in the percent of cases terminated with no appeal pending (ranked 35).

The Title XXI State Child Health Insurance Program in Louisiana has extended income eligibility for Medicaid to 133 percent FPL up to age 18 years. There is no state-only child health insurance program adopted in Louisiana as part of Title XXI. Managed care arrangements are required for nearly all children, including child SSI beneficiaries and those children qualifying for Medicaid under the non-cash-linked, low income eligibility aid groups.

The Family Independence Temporary Assistance Program (FITAP) is Louisiana's TANF program. The average FITAP cash grant is \$155 monthly with the maximum grant for a family of three of \$190, which ranks 48<sup>th</sup> in the nation. Beginning in January 1997, benefits received count toward the time limits, which are a maximum of 24 months in a 60 month period, and a lifetime limit of 60 months. The earliest that time limits could result in the loss of benefits is January 1999.

In the remainder of this section, we repeat the format established in Section 3, first summarizing the interviews with SSA office staff, then with Medicaid and other public and private agency staff, and finally with families in New Orleans.

## **6.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES**

### **6.2.1 SSA Regional Office, Dallas, Texas**

We interviewed a childhood coordinator in the Dallas Regional Office. The Dallas Regional Office covers five states including Arkansas, Louisiana, New Mexico, Oklahoma, and Texas. The Center for Disability in the Regional Office includes approximately 20 staff, which includes the director, a team leader, and two disability program analysts who supervise DDS activities. The office also has a childhood coordinator. Childhood issues are handled to some degree by all of the Regional Office staff. There has been some downsizing, largely through attrition, during the past few years.

#### ***Role in Policy Implementation***

When welfare reform first took effect, the Regional Office worked with the SSA Headquarters to develop the policies and procedures for implementation. As the workload developed, efforts were focused on getting the necessary processes in place to handle new implementation issues as they emerged. Once the policies and procedures were in place, the focus turned to training those making the eligibility decisions, which involved site visits to the DDS offices and training with medical support staff.

In terms of the ongoing caseload, the Regional Office received the listings of cases from SSA Headquarters and distributed the listings to SSA field offices. Because the implementation of new policies always involves a learning curve, the Regional Office played an ongoing role in training and monitoring. Welfare reform was a “high maintenance” rule change and required ongoing communication with medical and vocational experts and with medical staff to keep them up-to-date with implementation policies. The continued input to the implementation process from advocacy groups resulted in new policies that the Regional Office then communicated to the local offices as new instructions.

#### ***Agency Impact and Challenges***

**Staffing and training.** The workload has increased in the Regional Office although the same number of staff is available. The increased staff workload has made it difficult to provide other support to the district offices. Program bulletins that are distributed by the Regional Office largely pertain to the childhood disability rules rather than to other operations. It has become much more difficult to refine processes in the way that had been done prior to the implementation of the new rules.

The fact that the childhood workload was made a priority for the field was particularly difficult because the offices already were saturated with work, and because there are large volumes of childhood cases in the region. The Dallas Region had proportionately a larger volume of the potentially entitled population, and of the re-reviews. In terms of beneficiaries, Louisiana has a higher volume of childhood cases with the possible exception of Texas, and low economic levels in Louisiana are part of the

reason that there are higher caseloads in that state. Overall in the Region, the district offices got behind in the regular SSI determinations for non-medical reasons (income and resources), and this contributed to high stress levels among staff.

**Implementation.** The changes in direction in the policy implementation have been a significant challenge to the Regional Office. Implementation of welfare reform did not commence with all of the fully developed policies and procedures in place, with some policies and procedures evolving due to the involvement of advocacy groups.

There is a perception of a tendency toward allowing more cases than would have been allowed had the law been followed as originally written. The re-review process is one vehicle through which some pressure has been realized. Following the Top-to-Bottom review, there appears to be greater focus on inaccuracies that might occur in the denials, as opposed to the inaccuracies that might occur in cases that are approved or continued. This has caused some frustration within the DDS offices because while errors do occasionally occur, it sometimes appears that the rules are changing. This perception comes from the trainings that are delivered to the DDS, the feedback they receive from SSA Headquarters, and from the implementation of the re-review process.

Another major challenge in implementing welfare reform is related to MIS requirements. It has been difficult to achieve a centralized MIS that can serve the needs of the SSA offices. The childhood redetermination process was straightforward because these cases were part of an electronic database. However, the cases affected by the re-reviews have posed a major information systems challenge. The Regional Offices received a listing of cases to work from that was not part of an existing database. The electronic file established by SSA Headquarters—the “Linked Childhood File”—did not adequately describe the status of childhood cases. For example, it was not possible to determine whether a case had been to the DDS, whether it had left the DDS, whether the case was in a district office for redevelopment, etc.

Another related implementation issue is that SSA Headquarters has been using different data (from their internal data systems) to generate their reports than the DDS has been using to report progress to the Regional Office. The regions have been on their own in terms of tracking the cases. As a result, the DDS and Regional Offices are asked to justify their caseload status based on data reports generated from SSA Headquarters. There is some concern that SSA Headquarters and the Regional Offices are working from different databases and listings; recently the Dallas Regional Office requested a listing from SSA Headquarters so this listing can be compared with the listing that the Region is using to estimate progress.

One reason it is difficult to estimate the status of appealed cases is that some are appeals based on the initial redetermination, some are appeals based on the “failure to cooperate” re-review process, and others are appeals pursuant to the 1998 “good news” letter. Another contributing factor to the apparent discrepancies may be that appealed cases at the OHA level are considered to be “pending” by SSA Headquarters. An attempt was made to track the status of these different cases, but the process was too complex to

complete, and the MIS component at the Regional Office does not have adequate staff to generate the level of information that would be useful.

A current issue causing concern for the states is the process of determining Medicaid eligibility for the “grandfathered” children whose SSI benefits are terminated. It is still not decided how the states will make the disability determinations necessary to determine eligibility.

### ***Caseload Status***

The Regional Office estimated that approximately 99 percent of the child cases initially targeted for redetermination have been processed so far, with only a handful of cases remaining. Figures are not currently available on the status of the appealed cases, although there is an indication that the DDS estimate of processed cases is about 15 to 20 percent higher than the estimate produced by SSA Headquarters. In a recent teleconference, it appeared that the internal systems in the regions do not reflect figures from SSA Headquarters, in all regions.

### ***Experiences With Family Response and Impact***

The overall appeal rate for the Dallas Region has been high at about 75 percent. There are several possible reasons for this. Significant efforts were made by the SSA district offices to get people to appeal the cases, particularly early “failure to cooperate” cases. Even before the Top-to-Bottom review report, the SSA offices reacted to changes in the implementation process by generating a listing of child cases and recontacting families at the district office level to try to get families to appeal. Thus many families had the opportunity to appeal even before the March 1998 “good news” letters were distributed, and all cases were blanketed with the good cause provision.

According to the administrator we interviewed, Chicago and Dallas regions made these initial efforts to encourage appeals with approaches that were somewhat different. In the Dallas Region, the district offices contacted all families to encourage them to appeal, whether or not there was perfect documentation that the family had been informed of the appeal options.

There also were special efforts around benefit continuation issues. Special teleconference trainings were coordinated by the 6 area directors and conducted at the district offices with representatives or with the full office staff. These trainings, which were conducted around September 1997, focused on the explanations that were to be provided to families about benefit continuation options.

There was some indication that parents might be misunderstanding the benefit continuation procedures, although specific problems have not come to the attention of the Regional Office. If families appealed in good faith and met income and resource requirements, they would still need to go through a formal repayment review process, but it has been almost automatic for families to receive repayment waivers. The district office

emphasis may have changed over time to clarify for families that the waiver is very likely to be granted, ensuring that families understand that they probably would not need to pay back these benefits.

When the failure to cooperate cases were taken on, the district offices were asked to ask parents why they did not initially respond and appeal the child's case. The feedback was that parents had not completely understood the verbal explanations they received, and had trouble remembering what had been told to them. Parents also sometimes said that they had not completely read through the letters they received; once they read that there was a decision to terminate the case, they did not always continue reading the letter, which also described their options for appeal. The administrator we interviewed suggested that this may mean that the letters are too lengthy and not understood by parents. There may also have been language barriers for primarily Spanish-speaking parents. Finally, some of the parents may have learning disabilities themselves that make it difficult for them to completely understand the materials that are sent to them.

The administrator we interviewed stated that there may have been difference in impact across states due to the response from a state government. For example, the State of Texas encouraged families to appeal; one State service agency used the listings of potentially affected children provided by SSA to send letters to families, encouraging them to appeal the child's case. In general but particularly in some states, families have been bombarded with letters about their child's SSI.

### **6.2.2 SSA Disability Determination Office (DDS), New Orleans**

We spoke with an administrator with significant supervisory responsibilities for the childhood cases, a medical liaison officer, a hearings supervisor, and two DHOs. The DDS has approximately 130 total personnel. This includes 51 examiners (assigned to separate units) and 18 part time medical consultants; the examiners work within six regular operating units that are trained to work on all types of cases. There are four DHOs and one supervisor. The DHOs are assigned along with two hearings support staff members to a pilot program, called the Hearing Officers Temporary Staff (HOTS), which was established in October 1997 to handle the under-18 childhood cases. This unit was expected to operate for six months but is projected to last for three years; the purpose of establishing the special unit was to ensure that individuals were not inappropriately having their SSI benefits terminated.

#### ***Role in Policy Implementation***

The DDS inserted a new layer of hearings before the administrative hearing that had existed previously. A face to face hearing is now conducted in the DDS office, whereas the redeterminations for children turning 18 have been handled in the DHU, which is in a separate office and has always handled other adult hearings. Both the HOTS and the DHU only handle cases in which the child has been receiving SSI benefits and a benefit cessation has occurred; other cases skip this extra step.



### ***Agency Impact and Challenges***

**Staffing and training.** The major slowdown in the process was waiting for federal instructions in case handling that arrived in February 1997, when local training began. Overtime was necessary from June through August 1997 to meet the federal deadline for completing case processing (which then was extended to February). No major staffing changes were made to accommodate the new workload. Attrition of clerical staff and some medical examiners has reduced the overall staffing due to a hiring freeze that is in place.

A training emphasis had been placed on ensuring that mental retardation cases were not inappropriately adjudicated as not disabled. The medical liaison officer met regularly with the consultative exam (CE) physicians to make sure they were updated with the new standards and the medical record content requirements.

**Implementation.** A significant challenge to the agency resulted from the continual re-reviews of the same cases. This resulted in confusion on the part of the examiners, who got confused about whether they were handling the cases correctly and were making an effort to find something new and different that was not really there.

Coding was reported by those we interviewed as having been a significant challenge. Most of the errors identified from the redetermination cases reviewed in the Dallas Regional Office have been coding errors. Mistakes are made by examiners as well as by programmers although there has been improvement over time.

Handling the 17 and 18 year old cases was identified as one of the most difficult implementation issues. Instructions came in 1998 in how to handle the 18 year olds cases, in which a new initial decision rather than a comparison review is completed.

### ***Caseload Status***

At one time, the childhood cases represented approximately 50 percent of the office workload. The DDS has almost completed the redetermination workload and has approximately 50 cases remaining. However, the DHOs now have a huge workload (4,000 cases are currently pending statewide). The backlog exists in the DHU (which has hired one new position).

The DDS staff whom we interviewed did not know how many childhood cases are now at the ALJ level. It is not unusual for the ALJ level to be one year behind in cases, and the childhood cases are just now arriving at the ALJ level. The DDS staff also noted that new consultative exams may be necessary by the time the cases are ultimately heard.

### ***Experiences With Family Response and Impact***

Some of the DDS staff we interviewed perceived that a large number of the childhood cases have been appealed by families, and that the Spring 1998 "good news"

letter brought the proportion of families who appealed up to nearly 100 percent. It seemed to the staff we interviewed that SSA staff had gone to those families who did not initially appeal to encourage them to file an appeal and to request benefit continuation.

According to some of the staff we interviewed, parents are often very sophisticated and understand that the longer they drag out the process, the longer they will continue to receive SSI benefits. Children often miss consultative exam (CE) appointments, which is frustrating to the CE providers because SSA does not pay for no-shows. Also a number of children are living with guardians who are not legally responsible for them. In general, the staff we interviewed suggested that there is a strong community network by which families received information about SSI.

According to our interview, teachers may feel strong pressure from families to provide evidence of a child's disability. Parents have access to the child's records and often review these records at the DDS, which makes it difficult for teachers to indicate their judgment that the child is not disabled. After the *Zebley* decisions, SSA sponsored seminars that were attended by a number of teachers. Less outreach to teachers has occurred as part of the current eligibility redetermination process, although the medical liaison officer has talked to special education teachers in the New Orleans schools as well as mental health centers and the Children with Special Health Care Needs agency.

One staff member stated that following the *Zebley* decisions in the 1990's, children and families "bombarded" the mental health centers and once the SSI benefits started coming, there were a tremendous amount of closed charts at these centers. The DDS received numerous letters from clinic directors describing the overloading of the clinics that occurred following *Zebley*. Currently children are beginning to go back to those centers, but they often go to several different clinics for services; this created a large workload for the DDS in tracking down all of the records and finding missing charts.

### ***Local Policy/Resource Trends***

Because many children go to the charity hospitals for health care, and go to multiple facilities, it has been difficult to compile medical evidence from an ongoing provider, and in a number of cases a CE is required. The staff we interviewed reported that children who visit the charity hospitals often see a different provider on each visit and combined with the inadequate medical records that are often maintained, it is not possible for the DDS to call for clarification and additional details. The DDS staff interviewed had not observed any changes in medical records or in health care access due to implementation of Medicaid managed care.

### **6.2.3 SSA District Office, New Orleans, Louisiana**

We interviewed one supervisor and four claims representatives (two in the post-entitlement unit and two in the disability unit) in a district office in New Orleans, Louisiana. The district office we visited has 48 employees, including a manager, an assistant manager, three supervisors, two field managers, and 40 individuals in the units

(e.g., Title II, Title XVI). These staff include nine post-entitlement unit CRs, disability unit CRs, and nine service representatives. Staffing is unchanged since 1996 although attrition has resulted in a small decline in staff from about 52 to 48.

### ***Role in Policy Implementation***

The district office assistant manager performs public relations activities and as part of this role, informed advocacy groups and schools about the changes that were about to occur. The district office has a good relationship with advocacy centers in the New Orleans area, and there was collaboration to ease the transition.

The listing of childhood cases subject to redetermination included several thousand names. The office conducted interviews for the childhood cases every day for about a year. When families came to the office to have the redetermination letter explained, this was handled by the service representatives. Claimants who requested an appeal were transferred to the claims representatives.

Four claims representatives assisted the post-entitlement unit's seven or eight staff with the continuing disability reviews due to the work overload and the need to recontact a large number of families. Initially in 1997 there was an effort to finish the caseload by a certain date near the end of the school year. As a result, four of the faster interviewers were moved to these cases and completed about five to eight interviews daily.

### ***Agency Impact and Challenges***

**Staffing and training.** When the re-reviews from the Top-to-Bottom review began, staff had to work overtime and put other work aside. The childhood reviews added to the office's workload and left a lot of other work backlogged. No additional resources were provided for the Top-to-Bottom re-reviews, and overtime was not adequate to meet the workload need. The staff we interviewed stated that for the most part, the instructions received were straightforward and clear, and thus training was not a significant issue.

**Implementation.** The staff we interviewed stated that childhood eligibility changes had a significant impact on the schools because each child had forms that teachers had to complete. In particular, schools that served a low socioeconomic status population had to complete a large amount of forms in a short period of time, and teachers were not happy about this added workload. Some staff we interviewed stated that teachers report that parents in some cases encourage children to exhibit poor behavior to continue to receive the SSI benefits, and that some parents refer to SSI benefits as the "crazy check", which is disturbing to teachers as well as to SSA staff. Sometimes teachers have expressed to the claims representatives we interviewed that they want to teach good behavior rather than pay money to families for this problem.

The claims representatives whom we interviewed stated that they felt that they had become more lenient over time. Over time, they perceived that the staff had essentially

waived the 10 day time period for requesting benefit continuation. The claims representatives we interviewed stated that they were to encourage as many families as possible to request benefit continuation, although the staff stated that they had not been instructed to tell families what option to take. The staff we interviewed also felt that the language used to describe the options to families appeared to have softened over time, with some language left out and language added in that families could ask for an overpayment waiver. The CRs felt that parents rarely read the letters and instead relied upon the explanations of the CRs. Staff also went back and gave families “good cause” for their late requests; they re-contacted many people who had appealed without requesting benefit continuation and tried to explain the benefit continuation provision more softly. The CRs whom we interviewed felt there was a push for families to request benefit continuation because from the *Zebley* experience, it was thought that families would ultimately request benefits if not requested now. In general, the CRs we interviewed said that they felt they were instructed not to mention that the family might need to pay back the money.

**Dedicated accounts.** According to the staff we interviewed, the post-entitlement unit was just beginning to feel the impact of the dedicated accounts policy. The letters that families receive about their dedicated accounts do not state that families must get approval from the SSA office, and many parents do not understand the policy and call for clarification. The CRs we interviewed stated that it was impractical to place payments in a bank account but not allow parents to use the money, and that a trust fund might have been a better alternative. In general, the CRs also felt that it did not necessarily benefit the child SSI beneficiary to have access to special things that could not be used for the child’s siblings.

The CRs reported to us that they have not yet received any cases of families who are having to pay back benefits, although a few families have received such notices. While it was not known whether the office would waive or suspend collection, the CRs perceived that staff all along have known that the families would not have to pay back the money.

Of the small number of dedicated accounts established so far, the CRs we interviewed who had had contact with these particular cases reported that parents have not spent the funds as the policy guidelines had intended.

### ***Caseload Status***

DDS has finished the first redeterminations, and a significant number of families are trying to get eligibility restored through the OHA hearings. Some cases have moved to the ALJ stage although the district office does not have estimates. Several cases have returned from the ALJ level as cessations, but there are also a number of reversals in which the ALJ finds the child eligible.

### ***Experiences With Family Response and Impact***

The staff we interviewed stated that for the most part, families appeared to be aware of the changes and of what was going on during the policy implementation. The claims representatives we interviewed felt that many parents did not respond until the checks were stopped but then did respond at that point.

While the staff we interviewed did not have figures, it was estimated that appeals had been requested in around 80 percent of childhood cases. The “good news” letter sent to families in Spring 1998 brought in another 20 percent or so. The staff reported that there was no effort to discourage families from appealing, and they did not know why some families appealed and others did not. The CRs felt that most families who did not request benefit continuation may have had access to other income sources.

The assistant manager had not heard of any problems or issues related to Medicaid coverage for the affected population. This may not have been a major issue for families because many of the affected children did not need more medical care than the average child. The Office of Family Support (OFS) and SSA have a relationship at the state level, with a computer interface that allows SSI recipients to receive Medicaid coverage. When SSI eligibility is terminated, the message is received by OFS immediately (as part of daily downloads).

The CRs whom we interviewed had heard several parents ask about a letter they had received stating that their child would continue to receive Medicaid. The CRs did not recall receiving any instructions about Medicaid eligibility for the affected children. Few families have asked about Medicaid eligibility.

CRs felt that the largest impact of welfare reform SSI provisions was the loss in income for the entire family. Many families are not in the workforce so SSI is the only income source. Families have told the CRs that they will apply for welfare because they don’t have work skills, or because they have small children. Some parents are losing welfare benefits because of the welfare reform time limits, however, and the largest impact has not yet been felt, according to the CRs we interviewed. Few parents appear very concerned or “frantic” about the potential income loss, which some CRs felt was because they did not believe that benefits would actually be terminated.

The CRs felt that parents who are now newly applying for SSI childhood benefits are providing more detail about their child’s problem than has been provided in the past, particularly regarding behavioral problems.

No particular impact was seen for children in foster care; if OFS was the representative payee for a child, then the case was handled by the Baton Rouge SSA office.

### **6.3 SUMMARY OF INTERVIEW WITH MEDICAID AGENCY**

We interviewed an administrator in the Medicaid program's eligibility program with the Department of Health and Hospitals. The Department of Health and Hospitals administers the state's medical assistance program (Medicaid) in addition to the SCHIP, the Maternal and Child Health Block Grant, licensing and regulation programs, the state charity hospitals, and several other health programs. Medicaid is administered within the Office of Management and Finance. Louisiana is a state that confers automatic Medicaid eligibility to SSI recipients. Medicaid coverage for low-income children extends to children with family income up to 100 percent of the federal poverty level (FPL) (and 133 percent of the FPL for children under 6).

#### ***Response to the Policy Implementation***

According to the administrator we interviewed, the agency issued a policy to caseworkers based on the new eligibility group. Due in part to the active legal aid organizations in Louisiana, the agency has implemented an automated eligibility redetermination process to ensure that individuals do not drop from the rolls without due process and an eligibility assessment. When the Medicaid agency receives information from SSA regarding a child's loss of SSI eligibility, the agency initiates a redetermination process (also in place for the TANF program). The agency sends a one page form and letter to the family stating that SSA has indicated the child is no longer SSI eligible and thus that the child's Medicaid eligibility needs to be redetermined. Families are asked to notify the agency if they have appealed the SSI cessation and to complete and submit to a field office an enclosed form with questions about employment information, household assets, etc. The child's rights and responsibilities are listed along with a statement that Medicaid coverage will be affected if the family does not respond. If there is no response in 15 days, then the agency sends an advance notice of closure that informs the family of the potential loss in coverage.

According to the administrator we interviewed, if the child is found to be financially eligible at this initial notification of loss of SSI-linked Medicaid, then the child's Medicaid eligibility is continued for a year before a re-assessment is done. Initially HCFA instructed the states to complete this process in 45 days following SSI eligibility loss to maintain the FFP, but this was lengthened to 120 days due to the extent of the redetermination process. Most of the SSI childhood cases affected by the SSI changes were handled this way.

Medicaid and TANF programs are administered in different state agencies. The Department of Social Services' Office of Family Support administers the state's TANF program, which is called the Family Independence Temporary Assistance Program (FITAP), as well as the Food Stamps program, disability determinations services, and several other public assistance programs. The Medicaid agency contracts with the Department of Social Services to perform income eligibility determinations for Medicaid.

The administrator we interviewed felt that legal aid organizations have been helpful in getting both the Medicaid agency and the Department of Social Services to create and implement an "evaluation guide" that lists program eligibility. Caseworkers are instructed to use this guide when completing an initial application as well as when eligibility lapses in any aid group. The caseworker must be able to document that an individual's eligibility is comprehensively evaluated prior to a case closure.

In Louisiana, a special code indicating "affected children" was designated for the children under Section 4913 of the BBA. If a family indicated that they had an SSA appeal pending when they received the Medicaid closure letter, then their Medicaid eligibility was maintained. A large number of children are still in the appeals process. If the child's Medicaid eligibility was closed prior to October 31, 1997 then the child went through an eligibility redetermination process. The administrator we interviewed reported that more recently, there is a policy in place that allows Medicaid coverage to be re-established even retrospectively. If a family who never responded to Medicaid closure letters brings evidence to a caseworker that the child's SSI case has been appealed, then the Medicaid can be re-opened and provided retrospectively to the time of case closure. If the family has never appealed the SSI case, they can still apply for Medicaid but cannot receive more than three months of retrospective eligibility prior to certification.

Some parents placed the child on a TANF cash grant. For the many parents (mostly mothers) who wanted to get TANF benefits for the child, the child would automatically be designated as Medicaid eligible due to TANF eligibility. Thus not all children are in the protected group, although the State tracks these children with a special "affected child" code. Department of Social Services now conducts a second level of income eligibility assessment for Medicaid for children who are denied TANF benefits. The administrator we interviewed stated that initially HCFA did not designate the children who lost SSI benefits as protected, and thus the Medicaid agency did not assign a protected status to these children. The agency has now re-issued instructions based on HCFA regulation changes to protect the grandfathered group. To protect the eligibility of these children, during most of 1998 there has been a policy to advise parents whose child has moved to TANF rolls that the child is in a protected group, and that they should contact the caseworker if the child loses TANF benefits. The family has some level of responsibility, however, and a child could be dropped from the Medicaid rolls if the family does not respond at all to the closure notifications.

It was the perception of the administrator we interviewed that because many children's SSI cases are being appealed, there has been little impact of the grandfathering provision so far. The State of Louisiana is now deciding how to handle the future Medicaid redeterminations for this protected group. If more than a year has elapsed since SSA denied a child's case/last appeal, then the Medicaid agency would try to get medical eligibility information about the child, using the pre-1996 SSA disability eligibility criteria. Since May, the State has been looking into the possibility of memoranda of understanding (MOUs) between the agency and the DDS but has not committed to any specific arrangements so far. In all cases, the Medicaid agency would need medical information to determine whether the child continues to meet pre-1996 SSA disability eligibility criteria.

The Medical Social Review Team is the current entity within Medicaid that assesses medical eligibility; it uses SSA criteria but is completely separate from the DDS/DED.

Another implementation challenge is that the appeals status information provided by SSA Headquarters is often sporadic and inaccurate. While SSA offices have been responsive and the information they provide is reliable on a case-by-case basis, the electronic information provided often does not show an appeal status for an appealed case, and vice versa.

### ***Impact on Children's Medicaid Enrollment***

Because so many children have appealed the SSI cessation, and others were added to the TANF grant, the administrator we interviewed felt it is unlikely that many have lost Medicaid benefits. The administrator felt that many families had not responded to their Medicaid closure letters, however. While the agency has built protections into the eligibility determination system, it also has created more defined provisions for case handling in response to legal advocacy efforts. One potentially negative side for families is that the agency has to process cases in a timely fashion, with time limits for responses.

### ***Impact on Children's Access to Services***

In Louisiana, enrollment in prepaid health plans (PHPs) is mandatory for most child Medicaid beneficiaries, with the exception of children who are in out-of-home foster placements. SSI recipient status does not confer any exemption from PHP enrollment for children, and thus children who transition from SSI-linked to TANF-linked eligibility (or to non-cash assistance, low-income eligibility) for Medicaid would not experience a change in financing arrangement or provider.

## **6.4 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES**

### **6.4.1 Children's Special Health Services, New Orleans, Louisiana**

We interviewed a parent consultant to the Children's Special Health Services (CSHS) agency in New Orleans. The CSHS program in Louisiana has 17 parent consultants statewide. The parent consultants assist the CSHS program with policies and service delivery issues in the program that affect families. Louisiana has the highest involvement of parents in the CSHS/Title V program and is seen by the federal Maternal and Child Health Bureau as a model for other states.

### ***Response to the Policy Change***

The SSA Regional Office in Dallas organized a statewide coalition following the 1996 eligibility changes. The CSHS program helped to create and staff the hotline that was established following the policy change, in collaboration with Family Voices, which is a national, parent-organization advocacy group for children with special health care needs.



The coalition produced fact sheets that combined information about the eligibility changes and what parents could do, with information about how to contact and access legal assistance. SSA also provided status reports on the number of families who were affected and who appealed. The coalition conducted a mass mailing statewide. The coalition did receive some feedback from organizations, such as the State's bar association, on how many people responded.

The CSHS program also made fact sheets available in the CSHS clinics throughout the state. In these clinic-based programs, contact logs were maintained and there has been feedback to CSHS that some families had lost the child's SSI.

### ***Observations of Family Impact***

The parent consultant we interviewed felt that many families chose not to go through the appeals process because of the difficulty involved. The process was perceived as challenging and a "headache" for families, who had other demands, and thus some families dropped out of the process. The communications and documents from SSA were complicated and difficult for families to understand. Also, families perceived a burden of having to assemble medical records for the child, and this was overwhelming for some. There may have been some language issues for the Hispanic and the Vietnamese and Laotian communities that posed barriers to completing the process.

In terms of legal assistance, the parent consultant felt that families learned that they could appeal but were told when they sought legal advice that payments provided under benefit continuation might have to be paid back. The parent consultant felt that this may help to explain why many families did not seek legal assistance.

Of those families receiving SSI, many have not worked while others have worked only part time. Main income sources for many families are Food Stamps, and SSI, and this reliance on public assistance is due in part to the demands placed on them by the child.

Adequacy of insurance coverage was raised by the parent consultant we interviewed as an ongoing issue for families. The excitement over the new SCHIP program, which expands Medicaid eligibility in Louisiana, has been significant but has obscured the fact that Medicaid does not cover all things that families need. The loss of SSI-linked Medicaid means that a family has to re-apply for benefits. Also, in the Orleans parish, by the end of 1998 approximately 3,000 families will have their welfare income terminated. These changes are causing families to be upset and afraid, and they may not know that parents caring for children with special health needs might be exempted from the time limits enacted as part of welfare reform. While families are good at negotiating the systems when they understand them, they may not access services for which they are eligible when they do not understand the system or how to respond to the changes. The parent consultant we interviewed felt that another round of fact sheets for families specifically about the welfare reform changes may be necessary.

#### **6.4.2 Advocacy Organization**

We interviewed an attorney with the New Orleans Pro Bono Project. The New Orleans Pro Bono Project provides legal aid services and referrals in the greater New Orleans area.

##### ***Role in Policy Implementation***

The New Orleans Pro Bono Project was one of several legal aid/advocacy organizations that agreed to assist in the overflow of legal assistance requests that was expected following the 1996 childhood disability eligibility change. The New Orleans Legal Assistance Corporation was identified as the first point of contact following the policy change, with other organizations handling the overflow as necessary.

The Project also participated with other agencies in a statewide coalition when the eligibility changes first occurred. There was a significant effort to provide public information about families' rights to appeal and other aspects of the process, which was done in collaboration with SSA and providers within the community. A local hotline was created for families who needed services.

##### ***Response to the Policy Change***

In response to the policy change, the Project geared up by educating its volunteer pool about the eligibility changes and soliciting participation of attorneys to volunteer for the childhood cases. The project worked on getting these volunteers "engaged" in the issue. The flood of childhood cases that was expected never materialized, however. According to the staff member we interviewed, this was a surprise because Louisiana had such a high volume of childhood beneficiaries who were affected, and because as the process moved forward, Louisiana had a high number of eligibility cessations.

Several childhood cases have come to the Project following the SSI eligibility changes. These cases were referred to volunteers. In some of these cases, the clients have "dropped out" of the process midway, leaving the attorneys with the cases. Other cases are still in progress, particularly given the relatively slow timeline for the redetermination and appeals processes.

the staff member we interviewed did not know why few childhood cases materialized. It may be because families are confused about the process, but it does not seem likely that families are not pursuing assistance because they don't need it. It does appear that one private law firm in New Orleans has taken on a larger number of the childhood cases and has seen their childhood caseload grow since the welfare reform law was passed. The staff member we interviewed speculated that the private law firm may have attracted a larger volume of clients relative to the free legal assistance organizations because of the law firm's good marketing job regarding their specialization in these cases. The client community may be more aware of this organization due to the marketing, which could explain some of the low caseload numbers in the legal assistance programs.

According to the staff member we interviewed, the childhood cases have had less of an impact on the Project than the DA&A cases; the Project's role was more significant for the DA&A cases, because there was a homeless advocacy component.

The staff member we interviewed suggested that it has been a source of some frustration to build up a program to serve the childhood caseload, which requires motivation and recruitment of volunteers, when the caseload does not materialize. If a flood of childhood cases pursuing legal assistance suddenly appeared at this time, the staff member felt that resource capacity might not be there to respond to the volume because the volunteers assembled last year may no longer be "engaged" in the process.

## **6.5 SUMMARY OF FAMILY INTERVIEWS**

We interviewed eight families in the New Orleans area during the week of October 5, 1998. The parents of these children reported that the children had the following diagnoses at the time that they began receiving SSI benefits: asthma, attention deficit and physical disorder; emotional disorder; physical disability; hyperactivity and learning problem; asthma and behavior problem; audio disorder; emotional socialization problem; and speech and learning problems.

Four of the eight families reported that they had appealed the initial decision to terminate benefits for the child. Three of the four families who appealed had requested benefit continuation and were continuing to receive SSI benefits during the appeal. Three families had never appealed the cessation.

### **6.5.1 Experiences with the Redetermination Process**

#### ***Understanding of the Redetermination Process***

In general, most parents reported that they understood the letters and the other information they received from SSA about the new eligibility requirements and the redetermination process. Confusion was expressed by the four families who appealed about the current status of their children's cases because the families had not heard anything since filing the appeal about the status of the case status.

#### ***Appeals and Benefit Continuation Requests***

The four families who did not appeal the initial cessation provided several different reasons during the interviews. These reasons included missing the deadline due to health problems (one parent), believing that SSA was not considering the regular providers' records (one parent), believing that the parent would have to pay for the medical exams to substantiate medical eligibility, yet the child's Medicaid eligibility already had been ceased (one parent), and having physical barriers to getting to and communicating with the SSA office.

The parent of one child was in the hospital at the time that the notification letter arrived, and she believed that it was too late to appeal when she returned home and read the information. This parent did not know that her child could receive benefits while the case was being decided until she heard it from a friend. Another one parent did not appeal because she felt it would not do any good. She had reviewed the SSI file for her child when she had first applied for SSI for the child, and it never appeared that SSA had the records from her child's counselors, only the records from the physicians who saw the child as part of the SSA eligibility determination process. Thus, she did not believe that they would talk to or consider the reports from the child's regular counselor this time.

The payee for one child was an elderly relative whose own physical limitations made it difficult to negotiate the stairs down from their apartment to get to the SSA office. The guardian reported she could not read or write and has some difficulty hearing over the phone. Although the child had called the SSA district office about an appeal, the call was not returned and the family did not follow up. The other one of the four parents who never appealed said that to appeal, she would have had to provide additional medical documentation for her child's case to be reviewed again, but she could not afford the medical visits that it would take to produce these records. When her child's eligibility was denied, she was told that if she did not appeal then she would need to begin a new application process to get SSI benefits for the child. Thus she did not respond to further letters; she also did not recall receiving a "good news" letter in Spring 1998.

Of the four parents who appealed, one did express some reluctance at appealing. The parent stated that she did not want her child (now an adolescent) to receive SSI throughout his adolescent years because she felt that there would be a stigma attached to him that could affect his job prospects, particularly his opportunities in the military. A friend had only recently brought this to her attention. This was important to her, but she felt that this was not known by or considered by other parents, some of whom refer to SSI childhood benefits as the "crazy check". This was the reason this parent had mixed feelings about appealing and requesting benefit continuation following her child's termination from SSI.

Another one of the four parents who appealed had not appealed initially. She stated during the interview that she did not initially appeal because she believed it was necessary to receive benefit continuation during the appeal, and she did not want to have to pay anything back and thus decided against an appeal. She did appeal after receiving another letter in Spring 1998 because it was explained to her that "in some cases" families had to pay back money; it was the first time she had heard it phrased in this way and thus decided to try.

Only one of the four parents who appealed reported during the interview that she had sought legal assistance; this was the only parent who appeared to have gone through two eligibility cessations by the time of the interview. This parent reported that at an August hearing, the DHO informed her that she could ask for legal help/representation. She requested assistance from a local legal aid office, but they took a month to review her case and then told her one week before her hearing date that they could not represent her.

The parent told us that she did not know why she was not able to get representation. SSA did allow here a two-month postponement in the hearing date due to these circumstances. Another parent had sought legal representation for another child for whom she was seeking SSI, but not for the child who had lost SSI benefits.

## **6.5.2 Impact on Medicaid and Health Care Access**

### ***Medicaid Eligibility and Enrollment***

Parents of three of the eight children stated that the child had lost Medicaid eligibility after the initial cessation of SSI benefits. Of these children, one parent was able to get the Medicaid restored when she went to the welfare office several months later to get Food Stamps for the children (both in kinship foster care). In the second case, the other child (whose family did not appeal) was an adolescent whose Medicaid coverage has not been restored and who has now reached age 18. For the third child who lost Medicaid coverage, the mother was unable to restore the Medicaid coverage because her divorce from her husband had not been finalized, and the social services agency counted his income as her household income.

### ***Access to Medical and Mental Health Services***

Two of the eight parents reported changes in access to medical and mental health services following the SSI eligibility changes. Both of the two parents whose children had lost Medicaid coverage and who had not been able to restore this coverage felt that this had affected the child's access to care.

Access to mental health services was a problem raised by one parent. This parent's child had lost Medicaid coverage, and she was not able to have her child seen by a psychiatrist, although the child had many emotional problems; she had been hospitalized for suicidal tendencies several years before, and had begun leaving suicide notes again recently. The mother reported that the physician at the where the child had been hospitalized had told the mother that the child could get back in care if there was an effort to move the child to an out-of-home placement.

For one child who lost SSI and whose Medicaid eligibility was ceased, the child's mother was now paying out-of-pocket for the necessary medications and for the physician visits.

## **6.5.3 Socioeconomic Impact**

### ***Total Income Levels***

Total family income had declined for six of the eight families. For one of these families, the parent had applied and was receiving Food Stamps for the family after receiving the initial cessation letter, which increased total income, but had to quit her job

shortly after the letter arrived because she could no longer work and take care of the two children. Total income dropped in another family despite an increase in the parent's working income because of a divorce. In the two families, total family income had not changed significantly because they were continuing to receive the SSI benefits during the appeal.

None of the parents, all of whom were single, reported that they were receiving child support at the time of the interview. Two parents had tried to apply for child support after losing the SSI income. One of the parents completed the paperwork one year ago but has not yet heard anything from the agency, and said that she does not understand how the process works and whether she needs to follow up with the agency. The other parent who visited the child support agency said that she was told that because she was not receiving cash assistance (welfare), the agency could not help her get child support.

### ***Work Participation***

The parent in five of the eight families was working before the SSI eligibility change occurred. The three parents who were not in the workforce were either receiving Social Security (one parent) or SSI (one parent) or physically unable to work due to a recent illness (one parent).

Of the five parents who were in the work force, one parent reported having increased working hours after the SSI eligibility change. The other four of the five parents were working full time and did not increase their working hours or take on another job in response to the potential loss of SSI income.

### ***Use of Public Assistance***

Four families reported that they sought to obtain or increase their allotment of Food Stamps. One of these parents applied for Food Stamps but was found income ineligible because she was receiving SSI for herself and two children (one whose SSI benefit cessation was under appeal). One family applied and received Food Stamps when the SSI payments stopped (the SSI was restored several months later, pursuant to an appeal). Another parent was able to increase the family's Food Stamps by a small increment. Another parent tried to get Food Stamps but was told that her family was ineligible because of the car that she owned. At the time that their SSI income was first threatened, only one of the eight families was receiving any welfare income (with the exception of the grandparent who was receiving federal Title IV-E foster care payments for her other grandchild, who was not receiving SSI). None of the families reported that they had applied for welfare.

#### **6.5.4 Caregiving and Other Child Impact**

##### ***Living Arrangements***

Living arrangements changed for five of the eight families interviewed. In one of these families, there was a custody change in which the child moved from one parent's household to the other parent's household. The other of these five families had moved since losing the SSI income. Three of the four families who moved reported during the interview that they had changed residences due to the income loss. Among these three, two families moved into the grandmother's home, and one family changed residences because a child in the household (an SSI recipient whose eligibility had not been affected by the 1996 welfare reform changes) needed a cleaner home environment. The fourth family had become homeless following the loss of SSI income because this income loss occurred during a divorce, and thus the husband's support to the family was lost at the same time. This parent's increased working hours did not provide enough income to provide basic needs for the family, and one child lived with the mother in a friend's home while another child lived with the grandmother. The parent said that she was unable to get cash assistance because her husband's income continued to be counted as her household income. A church member had just made a low-cost rental available to the family at the time of the interview.

##### ***Child Care***

Only one of the families with young children reported having child care difficulties. This foster grandparent reported that the currently child attended an after-school center daycare program, for which she paid part of the costs as well as the child's transportation from school to the daycare center. The grandparent had recently quit her long-term job because the demands of her young foster grandchild required that she be available during school hours if the child needed to be brought home from school. One problem was that it was difficult to cover the child care costs even with the income from the previous job. Moreover, the grandparent was now looking for a swing shift job that would allow her to be available for the child during more of the day. This would require setting up a child care arrangement for the evenings, and the grandparent did not know whether this would be possible.

##### ***Preparation for Work/Independent Living***

The parents of the two children in their teen years expressed some concerns about their prospects for independent living. In one case, the parent of a child who had just attained age 18 and was a junior in high school felt that due to the support she was able to secure, her child would be able to make the adjustment of independent living. This parent felt that the special efforts she made to get her child the necessary psychological services (physical access to which was made possible through SSI), was making this transition possible. In addition to the ongoing counseling received throughout childhood, the child had participated in Big Brothers, was taking a city college computing course that the

child's teacher brought the child to on weekends, and received special tutoring from the teacher. The child's mother also kept in contact with the counselor and received "parenting" advice on how to encourage the child and handle the emotional problems. In the one other case, the elderly relative of a younger adolescent did not know what his job or independent living prospects were, particularly given his learning difficulties, emotional problems, and history of involvement with the juvenile justice system.

### ***Other Child Impact***

The grandmother of two children stated that taking care of her two grandchildren, whose mother continued to have a drug problem and unfit to care for them, had drastically changed her life and had been unable to find the kind of help necessary. She had quit a long-term job within the past year because the job did not allow her to be available for her grandchildren when necessary during the day. She was unable to get help from Big Brothers/Big Sisters, possibly because they were unwilling to come to the housing project, and her friends who initially helped her when she took custody of the children could no longer provide the respite care that she needed. She felt that the support available for grandmothers like her was "a disgrace" and was not sure how long she could continue to take care of the two grandchildren.





## **7. SITE VISIT SUMMARY: DETROIT, MICHIGAN**

### **7.1 INTRODUCTION**

Michigan was selected as a case study site due to its high volume of affected child SSI beneficiaries, its early implementation of welfare reform relative to other states, and its high penetration of Medicaid managed care. We visited Michigan during the week of August 31. We interviewed a total of nine families in addition to eighteen individuals in ten different agencies.

The State of Michigan had a 1990 Census population of 9.3 million with approximately 1 million living in Detroit. Michigan ranks eighth among states in the total number of children under age 18 (at 2.5 million). In terms of SSI participation in August 1996, Michigan ranked eighth among states in the total number of children on SSI and thirteenth in the proportion of children on SSI (1.7 million). Michigan also ranks second among states in the volume of child SSI beneficiaries with IFA (12,803 children or 30.6 percent of the child caseload) and fifth among states in the volume of child SSI recipients with maladaptive behavior (1,996 or 4.4 percent of the child caseload).

Wayne County (which includes Detroit) ranks highest among counties in Michigan in the total number of child SSI beneficiaries, total IFA and maladaptive cases (3,666), total cases subject to redetermination (5,521), and the total cases terminated with no appeal pending as of January 1998 (1,171). Wayne County ranked lower than a number of other counties in the percent completed of those cases subject to redetermination (ranked 18 of 213 counties)—likely due to the size of Wayne County's caseload—and in the percent of cases terminated with no appeal pending (ranked 23).

Michigan was one of the earliest states to reform its welfare program, with existing welfare program waivers prior to its October 1996 TANF effective date. Michigan's welfare program does not offer transitional child care or transitional Medicaid for longer than a 12 month period for welfare beneficiaries who are no longer receiving the public assistance.

In terms of Medicaid coverage, Michigan's coverage of low-income children has been expanded through Michigan's Title XXI State Child Health Insurance Program. Income eligibility for Medicaid has been extended to 150 percent FPL up to age 18 years, and Michigan's new, non-Medicaid state program (called MI Child) extends coverage for children 0 to 18 years up to 200 percent FPL. Cost-sharing for the state employee package that is offered under MI Child applies only to children with family income above 150 percent FPL.

Managed care arrangements are required for nearly all children, including child SSI beneficiaries and those children qualifying for Medicaid under the non-cash-linked, low income eligibility aid groups.

In the remainder of this section, we repeat the format established in Section 3, first summarizing the interviews with SSA office staff, then with Medicaid and other public and private agency staff, and finally with families in Detroit.

## **7.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES**

### **7.2.1 SSA Regional Office (Chicago, Illinois)**

We interviewed an administrator in the SSA Regional Office in Chicago, Illinois with responsibilities for childhood disability issues for the region. The Chicago Regional Office covers six Midwestern states, including Michigan, Illinois, Indiana, Minnesota, Ohio, and Wisconsin. The Chicago Regional Office currently has one full time person dedicated to childhood disability cases/implementation, and one person who spends 50 percent time on childhood disability. This is a significant staffing increase relative to staffing dedicated to childhood disability prior to the 1996 welfare reform law.

#### ***Role in Policy Implementation***

The Regional Office roles since the 1996 welfare reform law have included a number of visits to the DDS offices, and particularly contact with medical consultant staff and medical examiners. Visits to district offices also have been an important role for the Regional Office. The most significant role of the Regional Office has been serving as a conduit for information. There has been a steady stream of clarifications, and the Regional Office has operated a “hotline” in which questions are funneled through the Regional Office to SSA Headquarters, at least one time per week.

The Regional Office also has played a monitoring role, by heading up the Regional Childhood Review Cadre, which has existed for several months. The Top-to-Bottom review required Regional Offices to form review groups that can re-review cases in which the federal level found problems. The review groups are composed of the Regional district quality branch administrator, physicians, and DDS administrators. These groups either agree with the decision returned, or else send them to SSA Headquarters to the “national cadre”. There is continual feedback from the quality branch and the cadre.

Prior to welfare reform, the Regional Office had one person who had responsibilities for childhood disability and that person had 5 or 6 roles. Approximately 0.25 percent FTE was dedicated to childhood disability at that time, and this has increased to 1.5 FTE. No extra staffing was provided to the Regional Office for implementation. In fact, there had been downsizing prior to the 1996 welfare reform. Thus existing staff were pushed as much as possible. According to the administrator we interviewed, other operations may have suffered as the childhood cases became the priority, with the most significant effects on operations beginning in 1997 when the protocols were received from SSA Headquarters.

### ***Agency Impact and Challenges***

**Staffing and training.** This region has a number of psychologists and several pediatricians; one-third of the medical staff is psychologists, and there are three pediatricians. Because this already was in place, the staff was easily tapped to handle the increased childhood case workload. While not “medically acceptable” in previous years, SSA offices were instructed to involve speech and language pathologists in the determination process, whereas in the past, pediatricians had been used for speech problems. At this time, all DDS offices have recruited speech and language professionals, and each state has at least one. The DDS offices also have been somewhat more aggressive in obtaining school records (such as IEPs, and special education work-ups).

Regional Office staff has met with strong advocacy groups in the region. These advocacy groups were invited to the national Interactive Video Training (IVT) sessions, linked by satellite to SSA Headquarters. The purpose of these sessions was to preclude too much “trickle down”. In the past, the “train-the-trainer” model had been used, and the IVT resulted in less “local slants” in implementation of the rules. When issues arose, they were handled largely by conference call and occasionally by site visits.

**Implementation.** In terms of implementation challenges, the administrator we interviewed stated that some problematic patterns occurred in Illinois and in Michigan. In response, the Regional Office brought the managers together and brought a psychologist along to help with issues related to interpretation of test scores.

A volume of special instructions for case handling followed from the Top-to-Bottom review, particularly with respect to IQ scores in children. The instructions became quite convoluted and made it difficult for states to handle all cases correctly. This has caused some case processing problems because the DDS offices have had to return to cases to capture the necessary information. The offices already have looked at some of these cases more than once.

### ***Caseload Status***

The administrator we interviewed estimated that the vast majority (over 99 percent) of the childhood cases have gotten into the DDS and 95 percent of the cases are completed. Some cases were delayed for the CE or until school records could be made available, which sometimes involved a summertime delay until schools re-opened. It is more difficult to estimate the status of appeals precisely. The difficulty in estimating accurately the status of appealed cases stems from the complexity of the process and the multiple reconsideration options and payee decisions that affect case status.

In August 1998, the Regional Office sent to the district offices some new “failure to cooperate” appeals cases. About two-thirds of these cases never received any cooperation at all from the payee/family; often certified letters received no response, and parents sometimes failed to attend the scheduled CE for their child. This new caseload was expected to have a significant impact on the DDS offices in the coming months. There is a

large push for the agencies to stay current with the CDR cases and a special push for the LBW infant cases.

### ***Differences in Impact across States***

Several differences in caseload across states in the region were suggested by the administrator we interviewed. Ohio has had far more IFA cases, particularly IFA cases based on maladaptive behavior, than might have been expected. No specific explanation has been found for this finding; it is possible that it has something to do with how (and from where) children are referred to SSA in the first place, but it is not known.

The Regional Office administrator had no specific knowledge of how the State Medicaid Offices were handling the issues related to the cohort of children receiving SSI at the time that welfare reform was implemented (i.e., those children whose Medicaid eligibility has been “grandfathered” if they meet pre-PRWORA criteria). Lists of children potentially affected by welfare reform have been made available to states for this purpose.

### **7.2.2 SSA Disability Determination Office (DDS), Detroit**

We interviewed an administrator with significant supervisory responsibilities for the childhood cases, and with two DHOs (one with supervisory responsibilities). Initially, the DDS was in Michigan’s Department of Education, but it now has been moved to the Family Independence Agency. There are four DDS agencies in Michigan, and the Detroit office handles Wayne County. Due to the high volume of childhood cases, there are no particular units that handle the childhood cases. There currently are six DHOs.

### ***Role in Policy Implementation***

As in other DDS offices, medical examiner teams have made eligibility determinations at the initial and reconsideration phases. DHOs handle the disability evaluations for the appealed childhood redetermination cases, including the re-review cases, childhood and age 18 redetermination claims, and “re-noticed” appeal cases. Aside from the changes in eligibility criteria, there are no significant differences in the way cases are now handled.

In terms of Medicaid eligibility determinations for the “grandfathered” group of children, the State Disability Program was mentioned by the administrator we interviewed as a possible mechanism for assessing eligibility and taking on the continuing assessments. While the State Disability Program uses criteria similar to SSA in its disability assessments, the DDS staff we interviewed believed that the Program has not used the IFA as used by SSA following the *Zebley* decisions, and other post-*Zebley* childhood disability criteria. Instead, the State Disability Program’s population focus has largely been on short term hospitalizations and specific health conditions for which individuals need coverage.

### ***Agency Impact and Challenges***

**Staffing and training.** The childhood cases were a very large part of the DDS office's caseload. The Detroit DDS had the bulk of the cases for the state, which put the office behind in its overall caseload. It was difficult to gear up quickly because it takes an examiner at least a year to be able to do cases independently. Thus, bringing on new examiners produces a drain in the short term. This was the largest effect of welfare reform. The same group of officers who had been trained to do the DA&A cases were used for the childhood case hearings, rather than retraining another group. The number of DHOs has been going down, due to promotions and transfers. All but one of the twelve initially trained staff continued for the childhood cases, but the total number has now declined to six.

The hearings cases for the Detroit DDS did not come through initially as quickly as they did in other locations, so DHOs from the Detroit DDS began working in surrounding areas such as Ann Arbor. Now the area has been contracted to focus mostly on Detroit. District offices were added or subtracted from the DDS' coverage area rather than moving DHOs from one assigned office to another.

The interviewed DDS staff stated that the IVT served its purpose but does not provide the level of detail that would be useful as part of the training. In this training format, only a very small number of questions can be posed during the sessions.

**Implementation.** According to the staff we interviewed, the eligibility redetermination process has put a heavy burden on the DDS because the kinds of documentation necessary for SSI disability cases are not generally available in children's existing medical records. The Detroit DDS had a CE rate of approximately 70 percent, and thus the redetermination process was very expensive for this office. All CE exams are contracted out from the Detroit DDS; the contractor most likely had to add new pediatric staff to handle the childhood cases.

At the same time that work began on the childhood caseload in 1997, the office was installing new computers. Thus, there was a lot of change going on in the agency at the time. Some DDS staff felt that while the re-review process had not greatly changed what was being done in DDS offices, the process had introduced more confusion into the DDS with more focus on process than on outcome. The DHOs reported that it was difficult to know what SSA wanted in terms of outcomes. Initial feedback that the DHO we interviewed had perceived was that they were allowing too many cases, and later feedback was that they weren't allowing enough cases, or that they were being too specific or too harsh. It sometimes seemed to the staff who were interviewed that SSA was continuing to revise the adjudication parameters (e.g., the interpretation of the rules, the relative importance of the teacher's report, etc.) to achieve a certain ratio of allowances.

A related difficulty raised by some DDS staff involved the goals of the regulations and quality reviews. Recently staff heard that the intent of the re-review process was not specifically to allow more children, but instead was intended to prove that they had done it right the first time. This differed from the message that the staff felt they had received at

the beginning of the re-reviews. As with the redetermination process, during the re-reviews the DHOs whom we interviewed said that they were initially told they had been too harsh, and then told that they were too lenient and thus their cases would be reviewed. The staff we interviewed stated that this has not necessarily affected what the DDS was doing in terms of individual cases, but it has confused DDS staff. Welfare reform also resulted in more work reviewing what the medical examiners had done, to make sure that they were using the correct set of rules. Determinations for the children with borderline cases are where the trouble has occurred. The result of the recurring requirements to re-review cases is that some of the children's cases have been seen three or four times.

There have been additional challenges associated with the re-review in the DDS of all the "failure to cooperate" cases. While the staff we interviewed reported that they thought they understood and appreciated the intent of the policy to ensure that children are given every chance, this policy has not been helpful to the DDS in terms of its public relations. At least one staff member we interviewed felt that most are cases where the parent has clearly stated that they are not going to cooperate with DDS. Parents often have asked how many times they have to state this position. The "third-party" effort in which DDS asks parents who are not cooperating if there is another party who could take the child to the necessary exam, makes some parents upset because they believe they should make the decisions that affect their child. In general, the staff we interviewed felt that the overall impact of the incremental policies, and the re-review process, has been that the DDS has examined every possibility that a child may be eligible for SSI.

Finally, the staff we interviewed stated that there are some different personal perspectives within the office in terms of whether the childhood eligibility policy change was a positive change. There was a general perception among the staff we interviewed that a few extreme cases that may never have existed, drove sentiment about SSI provisions in welfare reform. It was suggested by one staff member that this perception apparently has continued despite the negative findings of the General Accounting Office (GAO) when these issues were examined. In any case, one staff member believed that the redetermination process could have been done more cheaply and efficiently if more time had been allowed for the implementation of PRWORA. More generally, in view of the impact on the agency and total costs involved, a preferred approach would have been to continue all children on the rolls until they reached age 18, then ceasing their childhood cases and using adult criteria, while applying the new childhood criteria to new applicants.

### *Caseload Status*

The office now is catching up with the childhood caseload. The staff we interviewed estimated that only about 60 or 70 hearings remain whereas several months ago there were about 200. The most significant impact came from the first redeterminations and then the re-review of the redeterminations. The last re-review only required the checking of a code.

A past policy to make an eligibility determination under the IFA where possible, and not continue on to a medical listing assessment, may have contributed to the agency's

large redetermination caseload. SSA policy generally has been to stop developing a case once a child's eligibility is established. Thus even if a child meets a medical criterion on the Listings, the office does not go further than in case development if there is already an allowance based on the IFA. Thus a large number of IFA cases actually could qualify for SSI under the Listings, but the DDS did not go after that additional documentation. One staff member we interviewed felt that this policy was the reason that the outcome of reviewing the IFA cases did not produce the result that others apparently had anticipated (i.e., resulting in a large number of benefit cessations). Many children have been continued under a different eligibility code. Staff in the past have perceived the IFA as potentially a quicker way to make the determination but had never had any idea that this eligibility classification would ever be used to decide which children might not be eligible for benefits.

Recently, the caseload of new applicants has dropped significantly, and this trend has included, but has not been limited to, childhood cases. This may be in part because of the improving economy. This decline in new applications has enabled the DDS to move more quickly with the CDRs.

### ***Experiences with Family Response and Impact***

A number of issues about families' responses to the eligibility changes were raised by the staff we interviewed. Parents appeared to have understood the basics of what they were supposed to do as the redetermination process started, even though they may not have read or understood the full text of the letters they received. One DDS staff member noted that with DA&A cases, there was an automatic appeal, whereas with the childhood cases, the parent had to actively appeal and visit the SSA field office. A reason that some families who did not initially appeal decided to do so following the March 1998 "good news letter", which offered families a second chance to appeal, may be that the families saw the series of additional appeal opportunities as encouragement.

Failure to cooperate has created more work for the agency. One staff member offered the example that sometimes the DDS has scheduled four CEs that have not been attended by the parent and child. At each level, this process needs to be repeated in terms of trying to get cooperation. Once the case reaches the a hearing, however, the DHOs tend to have less difficulty in contacting families. This might be because there is a perception among families that they need to get to the hearing to resolve the case. Some staff we interviewed thought this perception may be encouraged by attorneys saying that it is the hearing that provides the opportunity for reinstating eligibility.

While staff reported in the interviews that they did not know specifically how parents who were failing to cooperate differed from parents who cooperated with the process, a major reason that some parents have not cooperated is that the child has improved functioning (such as children who initially qualified for SSI as low birthweight infants, or who were having lots of trouble early on but got better as they got older.). When asked the "failure to cooperate" cases that are now being brought back again to the DDS, some staff we interviewed speculated that a small group of these parents may be



having problems in functioning just as their children do. The majority of these parents appear to be those who have stated numerous times that they will not cooperate, however. Some staff we interviewed felt that even though these parents had expressed this numerous times, their decision to not pursue the child's case further is not being respected in the sense that staff must make a certain amount of effort in each case.

A DHO stated that about 95 percent of families request continued benefits when given the option. This officer and a supervisor of hearing officers reported hearing that families not requesting continued benefits are primarily afraid of having to pay back the money.

One staff member raised the issue of trust, stating that many of the families served tended not to be trustful of government in the first place, and that families now feel betrayed by the system. The families were given the impression before 1996 that their eligible child would continue to receive benefits unless something changed, but then the rules suddenly changed. The cessations—and in particular the delays and incremental implementation in the process—were perceived by this staff member as aggravating the distrust that already exists. Another effect on families has been that the long period of time that elapsed between the initial letter about possible loss of benefits, and the ultimate determination (and re-reviews) may inadvertently have encouraged families to postpone making arrangements for their lives following the ultimate loss of benefits that may occur. Instead, families appear to be waiting for long periods of times without making these plans.

Finally, the staff we interviewed noted that almost no families have come with attorneys. It was suggested in the interviews that more attorneys may be secured among the children's cases once these cases reach the ALJ level. Given the huge backlog at the ALJ level, it could be years before these cases are completed, even though the childhood cases are a caseload priority.

### ***Local Policy/Resource Trends***

According to one of the DDS staff interviewed, the managed care expansion for Medicaid beneficiaries in Michigan has adversely affected the quality of care for children. While access to basic care may be improved by the expansion, quality of care has gone down. Many of the urban clinics that used to serve the children in inner-city areas are now closed. The providers that now are taking care of children do not have a lot of time to spend with the children, and thus do not take the time that would build a better medical record. Even with higher quality of care, however, providers would not be producing detailed information for their own purposes, such as the child's level of hearing.

According to one staff member, the schools have been somewhat ambivalent about the SSI eligibility redetermination process, possibly because the teachers are not personally in favor of all potentially eligible children receiving SSI. Often the teachers who respond to DDS requests for information express their own personal opinions and state that they don't believe the child should be getting SSI benefits. The DDS has not

wanted to put pressure on teachers to provide information. A workload issue is that there are five months out of the year when records are not available, including the summer months when schools are closed, and September through October when teachers say they don't know their new students well enough to provide assessments.

Finally, the DDS also has been somewhat affected by changes in its parent agency. The DDS was formerly in the Department of Education but now is housed in the Family Independence Agency. While DDS is autonomous and its policies and procedures are not significantly affected by its parent agency, the DDS agency is affected by the hiring freezes instituted by the Family Independence Agency (FIA).

### **7.2.3 SSA District Office**

We interviewed one supervisor and four claims representatives in a district office in Detroit, Michigan. The district office we visited has eleven CRs. The office added one temporary position for about one year to help with the increased workload. The staff estimated that over 50 percent of their caseload are childhood disability cases, particularly following the *Zebly* decision when word of children's eligibility began to spread in neighborhoods.

#### ***Role in Policy Implementation***

The District Office helps parents with filling out forms, as many parents have not completed forms when they arrive at the office. The CRs complete medical forms as well as continuation of benefit forms; the age-related function forms were new for the post-1996 redeterminations. When the end of the school year approached, the district offices were asked to pursue children's school records, and they got more involved with this than they had in the past. The records went directly to the DDS. Also, while the initial wave of letters were sent centrally, the district office followed up by contacting non-respondents. Finally, the "good news" letter was sent in the Spring to payees of children who had been ceased and not appealed, and to payees who had appealed but had not requested benefit continuation.

When the first letters were sent to families about their children possibly being reexamined under the new law, the SSA District Office sent a letter to all of the schools in their catchment area (about 30 to 35), stating that they would be willing to visit the schools to explain to staff how this law was going to impact some of their students, particularly in areas where mothers told SSA staff that all other children in their child's class were getting SSI. SSA staff planned to talk to school staff about how the households would be affected economically, and also how losing the SSI could affect the mother's interest in the child, for example. Only one (a junior high school) of the 30-35 schools responded, and the District Office sent staff to that single school.

The district office had a liaison in the Family Independence Agency who was helpful in trouble-shooting problems concerning Medicaid eligibility and a child's SSI case status. Some social services caseworkers are not able to fill out their own agency forms, and SSA

staff have to help them complete these forms. The district office counts on the FIA to inform them when the child has been taken off of an ADC grant, and this process can take months to get the information to SSA. SSA notification is not a priority for the social services caseworkers, who are already swamped with work. Often what has worked best (when the problem is getting the SSI payments started) is to get the parent to go to the caseworker, because the parents are highly motivated. In terms of communicating SSI eligibility information to the FIA, the CRs felt that the information on a child's case status goes relatively quickly from the SSA office to the FIA.

The district office has the authority to decide whether families must repay the benefits ("overpayments") that they receive on appeal when a case ultimately is ceased. Staff felt that in almost all cases, the SSA office was waiving the provision that families can be required to repay these benefits.

### ***Agency Impact and Challenges***

**Staffing and training.** The childhood cases were the largest group among the populations affected by welfare reform. The district office was given some resources to cover the required activities, including some temporary hires, overtime, and funds for supplies and other materials required to offset some of the costs associated with the welfare reform law. The supervisor we interviewed felt that the levels of staffing increases and overtime that were provided have been insufficient to get through the caseloads.

The initial reviews of childhood cases caused such an increase in workload that the district office had to farm out some of their caseload to nearby district offices. This took many months and was only completed after the end of the fiscal year; thus even farming out the caseload did not permit the cases to be completed before February or March. Staff fell behind last year with the redeterminations that were being processed in addition to the overpayment, CDR, and other functions, and have not yet caught up. The staff perceives they are "scrambling" to get through their workload; this is the first time that staff has been concerned about not getting through their required workload. One supervisor stated that the SSA Headquarters believes the district offices are overstaffed given the decline in caseloads, and yet the district offices are overwhelmed with the re-reviews and with the growing CDR responsibilities. Some frustration was expressed in the overwhelming workloads and in the fact that the office was unable to process all cases by the end of the fiscal year for the first time in 1997. It was demoralizing to the staff that they were scrambling to get caught up with their cases, yet hearing that the offices are considered to be overstaffed and not having overtime funds until nearly the end of the fiscal year.

**Implementation.** The CRs whom we interviewed felt that they were faced with continuing policy changes—from *Zebley* to the 1996 welfare reform law—and thus that they had almost continually been asked to change what they were doing, yet could not keep up because these changes were happening so quickly. Moreover, because the 1996 law was effective immediately, the policies were developed quickly at SSA Headquarters and distributed to regional/field offices; the more that the changes were reviewed and

regulations written, the more changes come down to the regional/field offices. The field offices have ended up with large binders of instructions, and it is often very difficult to know exactly how cases should be handled.

Family contact and case assessment responsibilities have increased significantly, according to the staff we interviewed. One staff member estimated that overall, about 30 percent of beneficiaries respond to an initial contact letter, another 35 percent require more follow up, and the remainder require significant effort. Also, medical forms are sent out to families with the letters, but these forms usually need to be completed at the SSA office with assistance from the CR because parents have not completed the forms prior to their office visit.

In some cases, staff completes age-18 redeterminations on cases that have been reviewed as part of the post-welfare reform redetermination process. The policy implementation process has been structured so that some of the cases are being evaluated first under childhood criteria and then under adult criteria within a relatively short period of time.

According to the staff we interviewed, the only periodic assessment that was regularly done prior to the welfare reform law was the capability assessment done of recipients to determine whether they were capable of managing their own funds. Prior to welfare reform, the claims representatives we interviewed felt that it had been rare for someone to come in to the office for a continuing disability review (CDR) related to medical improvement

**Dedicated Accounts.** The claims representatives raised the dedicated accounts policy required by welfare reform as a significant challenge. When the office owes the child more than six times the federal benefit rate (FBR) (which is currently \$494), this “windfall” payment (which generally has been the total payments accruing between application and eligibility approval) must be paid into an account that is dedicated to the child’s disability. While parents have unrestricted access to this account, they are informed that the money is to be spent on something related to the child’s disability. (These funds are not counted as a resource, and thus the regular SSI benefits can continue to be paid on a monthly basis.) CRs felt that the guidelines were too general and that the policy has been ineffective in part because it is too difficult to explain to families. For the most part, the families for whom dedicated accounts have been established have used the money for cars and other household expenses. On one hand, the CRs reported to us that they should have been given some control over the funds to ensure that they were spent in ways consistent with the guidelines. On the other hand, they expressed concern in their capacity to implement meaningful supervision and any control over the use of these funds, given the size of their caseloads.

Another increase in the ongoing workload has involved accounting functions. One time payments have increased three times since the welfare reform law was passed. Also, district office staff manually computes the dedicated amounts. This is becoming a significant workload because one part of the accounting workload is to record how

families report having spent the money, and each family with a dedicated account needs to account for how the money has been spent at the end of the year.

### ***Caseload Status***

The office processed about 861 childhood cases in the past year, in addition to the re-reviews. There are approximately 130 to 150 cases processed per month, with the additional workload representing about 25 percent above the normal (last year's) caseload.

### ***Experiences with Family Response and Impact***

The response rate of parents to the initial re-evaluations was fairly high. A large number of parents called for more information after receiving the centrally sent letter stating that the child may be affected by welfare reform changes. However, staff reported that families did not respond as well to the subsequent SSA letters about their child's case, and that multiple letters and staff time to follow up with families were required to get families to set and hold appointments.

The impression of the CRs was that the parents who did not initially appeal were those who thought their child was no longer eligible, or who did not want to come in to fill out the paperwork. They also felt that parents often do not read the communication, but will sometimes respond once they have received a large number of letters. Many did not respond until the checks stopped, and then they called to find out what had happened. Staff felt that word of mouth also affected families' decisions about whether to appeal and whether to request benefit continuation under appeal. Parents who initially decided against an appeal or against requesting benefits talked to neighbors; upon hearing from other family or friends that filing a "without fault" waiver would mean that benefits did not have to be paid back, the parents would then request benefit continuation.

The impact of the overpayment provision regarding appeals has been minimal. Some parents are paying back overpayments for typical reasons, such as overpayment based on income fluctuations. The CRs could not recall any cases in which families had to pay back benefits after SSI eligibility ultimately was denied pursuant to the welfare reform law. The staff stated that they had basically been instructed to waive payment for this type of overpayment.

For families who are receiving SSI, the loss of SSI income generally would have significant impact on the family because this income can be their only reliable support. Staff reported that mothers and fathers occasionally come to the district office to fight over who will get the SSI payment and who actually has custody of the child.

The impact of losing SSI income on children's access to services was perceived as relatively small for most of the affected families. The staff we interviewed stated that in a very poor community, most families need (and use) the money for basic needs rather than for the extra costs that may be incurred for a child with special health needs (e.g., placing

a child in a private school or getting tutoring services). Staff expressed concern that few families feel that the purpose of the money is to help with the extra educational and other needs of children with impairments. In fact, staff felt frustrated that parents did not mind that children would be “labeled” based on the diagnoses used to receive SSI, and that parents do not always work with the children to help them reduce the impact of their disability. This has contributed to some staff skepticism about the implementation of the dedicated accounts, in particular.

Impact on the child’s Medicaid eligibility appeared to have affected some families. A challenge that emerged was that FIA (welfare) caseworkers did not always appear to realize that SSA district offices did not handle Medicaid eligibility. Parents were sometimes directed by their caseworkers to the SSA office for these issues. Because the majority of families had been receiving ADC when the child became eligible for SSI, and then returned to ADC after SSI, Medicaid was unlikely to be affected for most families. Families rarely raised Medicaid as a concern, and many of the children were not receiving medical care or using their insurance. It was perceived that the majority of childhood cases in the office are learning disability related, and many of these children are not seeing doctors.

In terms of future income support, the majority of the children whose cases were undergoing redetermination were in families receiving public cash assistance (ADC), and it was thought that many families fell back on ADC.

According to the staff we interviewed, from what they hear from families it appears that teachers often believe that SSA provides a referral function to doctors or to services for children. Parents often ask for help believing that SSA does serves this function rather than being exclusively an income support program.

### **7.3 SUMMARY OF INTERVIEW WITH MEDICAID AGENCY**

We interviewed an administrator in financial services in the State Medicaid program (the Medical Services Administration) in Lansing, and a staff member of the Medical Consultative Division of the Family Independence Agency. The Medicaid agency was affected by a reorganization of public assistance and health programs in the State of Michigan that took place in 1995/1996. This reorganization resulted in three agencies—the Department of Public Health, the Medicaid program within the Department of Social Services, and the Department of Mental Health—being merged into one administrative agency called the Department of Community Health. The Department of Community Health includes the Medical Services Administration, the Community Public Health Agency, and the Behavioral Health Agency.

The Family Independence Agency administers other social services (welfare) programs and houses the Medical Consultative Division, which has 21 staff in Lansing who determine medical eligibility for the State Disability Program and for the Medicaid Disability Program.

### ***Role in Policy Implementation***

Eligibility for Medicaid is handled within the Family Independence Agency (Office of Operations), and thus is separated from the administration of the Medicaid program. The Medical Consultative Division conducts eligibility determinations for the State Disability Program and for Medicaid disability-related eligibility. Typically the small number of childhood cases that are handled are “child waiver” cases as part of the Section 1915(c) of the Social Security Act home and community based waiver that allows a child to receive services in the community rather than in an institution (,in such cases, a clinical team has determined that the child can receive services in the community).

Beginning in January or February 1997, due to the SSI childhood eligibility changes there was a significant influx of new childhood cases for the Medicaid disability program. As for other cases handled in the program, the process is that eligibility specialists meet with the family and pull together the medical records. The records are then examined in a paper review, which is followed by the eligibility determination. The program’s eligibility determination process mirrors the DDS eligibility determination process to a large extent. The program also has an appeals process that families can pursue following a negative eligibility determination.

When families who did not appeal their child’s SSI termination under the welfare law then turned to the medical consultative division for Medicaid eligibility, these families were informed that there was an appeals process in SSA that they could try to pursue. While many families had missed the SSA appeals deadline, a number of them were still able to claim “good cause” for the late appeal. This diverted some of the families from the Medical Consultative Division.

### ***Agency Impact and Challenges***

The large influx of childhood cases was not expected and had to be handled with existing staff. Prior to 1997, there were typically about 30 childhood cases per month. This caseload increased in 1997 to nearly 100 additional childhood cases per month. This volume continued through 1997 and tapered off in 1998.

No additional resources were made available to handle the increased caseload and the training requirements. The DDS office in Lansing assisted with the staff training that was required in the Medical Consultative Division to ensure that staff was familiar with the medical listings. DDS staff was sent to the program several times in 1997 to help with the training. All 21 program staff had to be trained in childhood eligibility because the program staff each are assigned to handle all cases on a geographical (county) rather than a case type basis.

### ***Observations of Family Impact***

The administrator in financial services had not observed any drop in Medicaid enrollment figures that would indicate that Medicaid coverage is being lost by children in

Michigan who lose SSI or are otherwise affected by SSI changes in welfare reform. According to the staff member in the Medical Consultative Division, staff are generally reporting that some families who chose not to appeal the SSI decision then turned to the Medical Consultative Division. Of the families who followed through with this process, about 40 percent of the children have had their eligibility approved. When this happens, families are advised to go back to SSA for an eligibility determination. About 60 percent of the families do not have their child's disability eligibility approved; some of these families appeal this determination, and others go back to SSA to try again or go to the social services office to determine whether they qualify under another Medicaid eligibility category.

No systematic reason that children would lose Medicaid benefits during the appeals process, or following benefit termination, was identified by the administrator whom we interviewed. Until families exhaust their appeals, the child should remain eligible for Medicaid. The staff member of the Medical Consultative Division perceived that most of the "grandfathered" child cases had their Medicaid eligibility reinstated.

## **7.4 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES**

### **7.4.1 SSI Advocacy Program, Michigan Family Independence Agency (FIA), Lansing**

We interviewed an administrator in the SSI Advocacy Program, in Lansing, Michigan. The SSI Advocacy Program was formed in 1979, and currently is staffed by fifteen advocates and one program manager. The primary function of the SSI Advocacy Program is to assist individuals who receive State Disability Assistance in applying for SSI. These individuals have qualified for Medicaid through a disability-related aid group. Because the criteria for disability-related Medicaid is the same as the criteria for SSI, most of them should qualify for SSI. Nationally approximately 70 percent of these individuals would be found SSI eligible if they applied (and made it as far as) the Administrative Law Judge level. Thus the objective of the SSI Advocacy Program is to get them through the process up to the hearings level, if necessary.

#### ***Roles for Children With Disabilities***

The SSI Advocacy Program has organized to provide representation to children, mostly those in out-of-home foster care placements, during their SSI eligibility determination. Recently the FIA has launched several special programs related to children and SSI. With input from advocates, a pilot program was developed to screen the full foster care caseload to identify children who might be eligible for SSI. The FIA issued a contract for the screening of children's medical records for the purposes of identifying potentially eligible children. This has largely meant a tightening of current policy to screen cases for potential SSI eligibility, rather than a completely new policy. This pilot has concluded and the results are being evaluated to determine whether this or a modified process should be pursued.



There also is a program in the FIA (also conducted through a contract) to screen child AFDC/TANF beneficiaries for potential SSI eligibility. Children with potential SSI eligibility are being identified based on the presence of a school-based services Medicaid service code flag, indicating that they had received medical school-based services. Using this code is less invasive than other ways that Medicaid data could be used to identify potentially SSI-eligible children, such as through Medicaid procedure and diagnostic coding.

### ***Response to the Policy Change***

In Michigan in particular, there was significant attention after the 1996 policy change to the potential impact on Medicaid eligibility. The FIA's policy for the children whose SSI was terminated has been to keep the children on disability related Medicaid status. The administrator we interviewed did not know how many children had been transitioned from SSI-linked to other disability-related Medicaid eligibility categories. FIA did make an effort to educate staff about the policy so that children's Medicaid would not be affected inappropriately.

There has been an increase in the number of children transferred from SSI to AFDC/TANF, due to negative outcomes of the SSI eligibility redeterminations. The SSI Advocacy Program has served children making this transition in terms of their Medicaid and Food Stamps eligibility. Usually these children move to their parent's AFDC/TANF grant after SSI benefits are terminated. This has created an extra workload for the agency. It also has increased FIA expenditures because the State of Michigan is now bearing the cost of the child's cash assistance, which generally is about \$90 per month (with the state paying 50 percent of the cost). Overall, the policy change also has increased the workload in the entire community, in the sense that there are advocacy groups and others putting resources into assisting the affected children.

In general, the availability of Medicaid in Michigan for children under 21 has meant that it is rare for children to be in the disability-related Medicaid coverage group, unless they are receiving SSI. Less case development and workload is required to place children in an income-related eligibility group than the several hours or so that is required to establish eligibility based on disability.

### ***Observations of Family Impact***

The largest observed effect on children and families has been confusion about the process. So far there has been no significant impact observed, although those families affected by losing SSI would certainly be feeling the impact. Possible reasons mentioned for the impact being less than expected include: some of the affected children may not be part of the caseload served by the SSI Advocacy Program; some children made a simple transition into AFDC/TANF; the initial projections were high and SSA relaxed its rules; and some children's health and functional status have improved.

While there was advocacy for a federal response (such as the grandfathering provision that was adopted), and the State of Michigan took steps to sustain Medicaid enrollment for affected children, it would be possible for children to fall from the Medicaid rolls if their parents did not pursue ongoing eligibility. Also, while children's loss of SSI eligibility may not immediately affect their Medicaid coverage, the loss of SSI puts the children's coverage back into the state arena. This results in less stability in coverage because there are many things that can interrupt Medicaid enrollment for beneficiaries of AFDC/TANF case assistance, including income fluctuations, potential sanctions under the new welfare reform work requirement provisions, etc.

The administrator we interviewed said that according to the eligibility program staff, SSI claimants are reporting to them that the Michigan DDS has been making an extra effort to develop the cases, to establish children's eligibility for SSI where possible.

#### **7.4.2 Mental Health**

We spoke to a state employee who has been a staff member of a public mental health hospital in Michigan. As a caseworker responsible for arranging out-of-home placements for children who have required hospitalization for mental illness, this individual was helpful in describing the role of the placement referral process in getting children with mental health problems enrolled in SSI.

Michigan implemented an SSI referral program following the SSI childhood eligibility expansion pursuant to the *Sullivan v. Zebley* decision. Michigan found that a large proportion of children in out-of-home care was meeting SSI eligibility criteria, and that federal funds could be obtained for these children. The State then mandated that families with a child moving from a mental health inpatient facility to a mental health department funded out-of-home placement apply for SSI. The caseworkers at the inpatient facilities helped families through this process. This offset state and county expenditures for out-of-home care. The inpatient facility caseworkers did not complete referrals to SSI for children if their enrollment was not part of a placement issue (i.e., for children who were not moving to out-of-home placements).

SSI enrollment was described as slow and cumbersome but as a process that has worked well. Also the mental health agency has been able to obtain retrospective SSI payments when a child's SSI eligibility is approved. According to a Title V administrator we interviewed, there has never been a broader, population-based initiative on SSI enrollment by the community mental health agency. To the extent that the agency focused systematically on facilitating access to SSI for children, the efforts focused on children in out-of-home placements under the auspices of the community mental health agency.

#### ***Observations of Family Impact***

The major benefit of receiving SSI income for children in out-of-home placements has been the automatic eligibility for Medicaid. No additional case management or other services are made available for children specifically due to their SSI eligibility. When

families have reported that they are losing the SSI income, they appear to have greater concern about the income loss than about what losing SSI will mean for accessing needed services.

### ***Local Policy/Resource Trends***

There has been a significant reduction in the types of services available for children with mental illnesses, according to the staff member we interviewed. In the past there were 400-500 inpatient beds, and there are currently only about 120 inpatient beds for the entire state. As de-institutionalization has occurred, everything in the public mental health care service system has been “notched down”. Thus children are moved from inpatient facilities just as other children are moved from residential to in-home arrangements. The service constraints in mental health services also have grown. On the outpatient side, where a child might have seen a therapist for 6 months, now only 6 to 8 visits are allowed. Also, 90 day waiting lists for services are filled and a number of families are not even able to get on the waiting list.

The MI Child program (Michigan’s Title XXI Children’s Health Insurance Program) was identified as an important resource for families whose children lose SSI-linked Medicaid eligibility.

### **7.4.3 Title V/Children with Special Health Needs Services**

We interviewed an administrator in the Medicaid program (Medical Services Administration) in addition to an administrator in the federal Title V Children with Special Health Needs Services, both in the Lansing Department of Community Health. There are between 6,000 and 8,000 children receiving SSI who may be eligible for Title V/CSHCS services. About 23,000 children in Michigan receive services through the CSHCS program, and approximately 48 percent of these children are enrolled in Medicaid. The Title V program is now part of the Department of Community Health along with the Medicaid agency.

### ***Roles for Children with Disabilities***

Historically, there has been a relationship between Title V and SSI due to the partial intersection of the program populations (with many children having dual eligibility). The CSHCS program does not provide case management or supplemental services for children receiving SSI who do not have Title V eligible qualifying conditions. However, the program does use infrastructure through the local health departments to enhance identification of children who might be eligible for SSI, and the program also assist in aggregating medical information that could be used to expedite a disability determination for a Title V eligible child. Other than habilitation services, there are few services that are not a Medicaid benefit in Michigan.

In the 1980's, a special program within the Department of Community Health, called the SSI Disabled Children's Program, was implemented to extend case management functions of the Title V program, as a public health program, to children receiving SSI. This program has special federal funding associated with it. Before it was block granted, there was a very active outreach component for children under age 7 years. According to our interviews, it became clear after a year that because of how the broad array of services are structured, including a special education entitlement that starts at birth, there really were no identifiable services gaps attributed to the child being on SSI as opposed to being in other programs. There is an active Early On program serving young children, and an active community mental health system.

According to one administrator interviewed, one of the reasons that the CSHCS started using information from DDS differently about SSI-eligible children is that they had no authority over the mental health agency. The mental health agency can obtain referrals from DDS of SSI-eligible children that their system covered and that CSHCS did not cover; however, this does not have a major impact in the community because mental health does not reach out to families on a population basis. Because the public health agency was not in a position to provide the services that mental health does, the focus became improving family and agencies' knowledge of SSI, and then focusing on families getting enough information about where to go for services once they are on SSI or on Medicaid.

Historically, CSHCS has had formal relationships with local (county) public health agencies, and FIA and public health agencies worked together to identify and increase awareness of FIA in terms of SSI. Children receiving SSI are referred to local health departments. Over time, it was one administrator's perspective that as managed care and other politics and pressures affected the agency, the focus on child SSI beneficiaries has diminished.

Thus several agencies have helped to promote SSI enrollment. There was a special initiative in Michigan about four years ago to increase advocacy for children in households receiving public assistance, to improve their economic situation; applying for SSI benefits was a mechanism for achieving this objective. The SSI disability children's initiative in FIA had special funding for case finding within the public assistance caseload, focusing initially on children in foster or other out-of-home placements. The objective was to review case files, ensure that the documentation was there, and to expedite referral to DDS. In addition, the public health department implemented efforts to ask families specifically about SSI, when they entered some part of the system, to identify children who might be eligible and to assist them in putting together that part of the case file.

### ***Response to the Policy Change***

No specific policy effects or responses to the policy change were identified for the CSHCS agency.

### ***Observations of Family Impact***

According to one administrator, it is the hope of the CSHCS agency - although they have no way of tracking it - that there will be no children who lose Medicaid simply because they no longer meet the SSI disability definition. For children who lose Medicaid eligibility because of changes in family income, the new children's insurance plan may be a resource.

The loss of the additional income is an important impact to families. This is in part because there are significant out-of-pocket costs in caring for children with special health needs; these include increased utility costs, wear and tear on carpets and household items and clothing, and also on family relationships. For many families, the SSI income is used for meeting basic needs rather than for specific medical needs of the child.

### ***Local Policy/Resource Trends***

The Medicaid program requires managed care enrollment for children with SSI-linked Medicaid, but managed care has been voluntary for children with Title V-eligible medical diagnoses. The recent experience of the Title V program with managed care enrollment of Medicaid beneficiaries is that a significant number of children are being identified to and enrolling in the Title V program to avoid having to enroll in the health plans.

#### **7.4.4 Detroit Public Schools, Special Education**

We interviewed an administrator in the Office of Specialized Student Services, in the Detroit Public Schools. The Detroit Public Schools operate a system with 187 elementary schools, 57 middle schools, 20 senior high schools, 5 vocational centers, and 16 special schools. There are approximately 180,000 children in the Detroit Public Schools. Of these children, about 18,000 are enrolled in special education, and approximately 2,000 of these children have a severe impairment.

### ***Roles for Children with Disabilities***

Teachers in the public schools provide evaluations for children who apply for SSI benefits. Other staff in the public schools who provide support services—including occupational therapists, physical therapists, psychologists, and nurses—also are involved in this process. Parents also ask the schools about forms that they receive from SSA in the mail when they have not seen them before.

The administrator reported that SSA offices have a good relationship with the Office of Specialized Student Services; SSA staff meet with and bring brochures for office staff. The schools have not traditionally conducted any type of systematic, proactive “outreach” to families about the SSI program, although in-service trainings have been conducted for staff about the services available for severely impaired children, and these in-services include information about SSI. There is no other systematic outreach or

information dissemination on the part of teachers. In terms of the services offered, the schools do offer some after-school programs and have some distance learning services, but do not offer tutoring services other than their regular special education programs.

### ***Response to the Policy Change***

Due to the eligibility redeterminations required under the 1996 welfare reform law, teachers in the public schools have had to provide documentation of student's functional abilities. This has increased the demands on teachers in terms of record-keeping and in terms of student evaluations. It also has increased the workload of other school staff involved with these students, including nurses, psychologists, therapists, etc. Thus the predominant effect has been caused by the increase in the volume of claims and forms that teachers need to complete. There have not been significant training costs or changes in the training of school staff regarding SSI.

In general, when the claims that families file with SSA are rejected, more extensive testing of the child is done. It seems that recently more claims have been filed and rejected than in the past. The administrator we interviewed stated that while overall the number of new applications has declined since the 1996 welfare reform law was passed, a number of parents have reported that their children are more impaired than they had been known to be. For example, after their children's cases have been reviewed and terminated, some parents of children with learning disabilities have said that the child has an autism problem, or another problem other than a learning disability, that would make the child eligible for SSI.

Another issue that has emerged is that some children are not receiving Medicaid after SSA redetermines their cases. This results in an increased demand for equipment and for materials from the school system. When equipment or other materials are needed for a child and are related to the child's education, the schools are required to obtain them for the family. The administrator we interviewed did not know why the Medicaid eligibility was being affected, but suggested two likely possibilities. The first is that information system difficulties in the Medicaid program may have occurred, and the second that some families do not follow through with the Medicaid eligibility determination process, particularly because there are not enough supports for families to know how to ask for what is needed.

### ***Observations of Family Impact***

A significant impact has been observed for older students. About six years ago, the public schools began a program of transitioning the older students with impairments into work opportunities. This program has been successful with the students who tended to be more "trainable" in particular. However, following the policy changes, parents of students receiving SSI seem to have become more fearful about their children participating in this transitioning program. Parents appear more fearful about having their children go out into the workforce because they believe that their children would lose their SSI benefits as a

result. While school staff has tried hard to convince parents that this is not going to happen, it has not been possible to reassure all of the parents.

### ***Local Policy/Resource Trends***

Michigan currently is implementing a “back to work” program that is affecting families receiving both AFDC/TANF and SSI. For some of these families in which parents are getting jobs, child care is taking up a significant part of their income. One challenge for parents is finding child care arrangements in which the caretaker is competent to care for the child given the particular impairment(s). Another challenge is finding the respite care that they need. Some of the children have verbal impairments and/or have aggression problems that make it hard for parents to find willing caretakers. Daily care is needed for the children, but the jobs that some parents find are not well paying enough to support the costs of the childcare. Parents frequently ask the schools for “latch-key” after-school services, but schools do not have the adequate resources.

### **7.4.5 Michigan Protection and Advocacy Services**

We spoke to a staff member of the Michigan Protection and Advocacy Services (MPAS) based in Lansing, Michigan. Protection and Advocacy has a \$3.6 million annual budget. Attorneys with MPAS provide legal representation and legal counsel to eligible persons, and also provide legal technical assistance to private attorneys who work on disability issues. MPAS also provides training and seminars in Michigan on legal disability issues. Specific programs operated for children with disabilities include the Advocates Supporting Solutions in Education (ASSET) network program that trains parent volunteers on advocating for children with disabilities, and for their children in special education. MPAS also operates the Michigan Self-Help Clearinghouse that provides workshops and training to many Michigan groups and national organizations.

### ***Role in Policy Implementation***

Protection and Advocacy started to participate in the childhood SSI issues when the American Bar Association became involved. Protection and Advocacy volunteered to provide the hotline, which would send families who called to the legal aid in their area, beginning in October 1997. If a family returned from legal aid to Protection and Advocacy, then representation was facilitated for them.

The MPAS provided comments early on with the implementation regulations. MPAS also provided representation for a small number of cases, and developed training materials for private attorneys. There has not been a significant amount of pro bono activity and attorneys volunteering to work on the childhood cases. In retrospect, not only did few attorneys volunteer, but the “floodgates” of families that were expected did not materialize.

Several months ago, the SSA Commissioner issued the “good news” letter that allowed families an additional opportunity to appeal. An error in the information mailed to families resulted in the Michigan Protection and Advocacy hotline number not being included in the materials (the Massachusetts number was used by mistake). This could have contributed somewhat to the less than expected number of family responses and appeals.

Following a meeting held with DDS in Spring 1998, the state coalition effort began to lapse. Some issues of case handling delays were raised, but little detail about the redetermination process was shared and discussed. The lapse in the coalition effort was partly attributable to the shift in focus to those children who were losing Medicaid coverage after losing SSI benefits, which was a significant problem. FIA was working to see what was causing what was happening so that they could stop the problem.

Protection and Advocacy staff also met with a Member of Congress from the Michigan delegation recently about the childhood SSI policy change. Two parents participated in the meeting; one parent had a child losing SSI who had significant physical problems, and another parent had a child with an ADHD problem underlying previous SSI eligibility. The Congress Member reportedly stated that it was the second family that Congress had hoped the legislation would target in limiting eligibility.

### ***Response to the Policy Change***

The Protection and Advocacy office used an existing hotline to handle inquiries about childhood SSI cases, and thus few extra costs were incurred by the agency due to the policy change. Staff anticipated more calls than were received, and thus the impact on the agency was less than originally anticipated.

### ***Observations of Family Impact***

The staff member offered some possible reasons that some families may have chosen to appeal while others did not appeal, and why some requested benefit continuation during appeal while others did not. Some families may not have understood the letters they received. Also, because certain categories of children were targeted by welfare reform, these families may have perceived that they were getting the message that their appeals would likely be futile. The redetermination process may have frightened some families.

The staff member did not have any information about how the Medicaid eligibility for children losing SSI in the “grandfathered” group would be determined in an ongoing basis. An ongoing issue was whether *Zebley* criteria would be used (MPAS has advocated for this). The primary Medicaid issue for advocates has been whether the children would be continued on Medicaid until they reached age 18, or whether their eligibility would be redetermined annually, and then whether the determination would be made under the old *Zebley* standard or under the new standard. There was massive confusion about this, and Congress had not done enough to make that clear.



The Family Independence Agency (FIA) has sought to determine why Medicaid eligibility problems were occurring for some of the children affected by the 1996 welfare reform law. The FIA sought the listing of affected children from the federal SSA office so those problems could be identified. However, according to the staff member we talked with, the listings provided by SSA were “useless” to the FIA, in large part because the data was incorrect, and also it did not provide the necessary information to solve the problem. In an effort to prevent children from losing Medicaid coverage when they remained eligible, the State FIA agency developed its own policies for caseworkers handling Medicaid eligibility for families. Caseworkers were instructed that children should not just lose Medicaid coverage, but instead that Medicaid coverage should be reinstated when Medicaid eligibility linked to SSI recipient status ended. However, according to the MPAS caseworker, the State FIA has been massively cut back in staffing over the past few years, and this has resulted in caseworkers being demoralized. This also means that the caseworkers find it especially difficult to absorb new changes. Thus the major issues were getting the computers and the caseworkers to absorb the changes required by welfare reform.

The staff member did not know whether the Medicaid problems were continuing. Few calls have been received by MPAS about this problem, but few calls have been received since the policy change anyway, and thus this may not mean that problems are not occurring.

### ***Local Policy/Resource Trends***

Current Medicaid policy in Michigan permits opting out of the managed care expansions only for dual Medicaid/Medicare beneficiaries, and nursing home residents along with a few other small eligibility groups. Children receiving SSI-linked Medicaid are not excluded or voluntary enrollment groups for Medicaid managed care, and thus SSI recipient status does not confer a special voluntary status in managed care for children.

A significant issue for advocates in Michigan has been the implementation of the Child Health Insurance Program (“MI-Child”) and the planned creation of a “seamless” system of health insurance for children in low-income families. There is an issue of needing to refer children to the appropriate caseworker rather than having SCHIP workers sign up children for Medicaid, and vice versa.

Finally, a significant issue has been the reorganization and the massive cut backs to the FIA, and the resulting demoralization among caseworkers and staff.

### **7.4.6 Children’s Home of Detroit**

We interviewed an administrator in the Children’s Home in Detroit. The Children’s Home serves children with emotional impairments through its resident treatment programs for children ages 6 to 17, respite care/emergency shelter, and a community service program. Approximately 150 children are served at any given time. About 673 children had been served between January 1998 and August 1998, an increase from a total of 618

in 1997. Funding to support operations comes from private sources, the Family Independence Agency (FIA), and from court funds. All children are voluntary placements with some but not all in protective services.

### ***Roles for Children with Disabilities***

The facility often becomes the payee for child SSI recipients who are admitted to the Children's Home. For most children, an SSI application already has been completed prior to admission because SSI applications are required for children referred to out-of-home placement through public agencies (courts, mental health, protective services). When the child is referred to the home, the referring caseworker goes over financial, medical, and other records prior to admission. The parent is expected to ensure that the child has Medicaid or private insurance, and the state mandates that they go to the SSA field office and apply for SSI. After about one month, the Home will ask to be the representative payee, assuming that the mother or father has gone to SSA already.

### ***Response to the Policy Change***

The administrator had attended a meeting at the SSA field office about the childhood SSI eligibility changes and redetermination process at the recommendation of the SSA field office. The biggest impact of the policy change has been the backlog in new cases created by welfare reform at the SSA district office. New applications are not being processed at nearly the same speed as they had been in the past. The paperwork is backed up because they needed to perform manual redeterminations, and newer cases (of children entering the Home, for example) were thought by the administrator we interviewed to be of a lower priority. While the administrator we interviewed emphasized that this is a temporary situation, the administrator estimated that while usually up to 90 percent of children in the Home were receiving SSI, while currently less than ten percent of the children were known to be receiving SSI. The administrator reported that while a small number of children served by the program are not income eligible, most are income and medically eligible and thus should be receiving SSI. The administrator stated that the benefits for approximately 300 children were expected but had not yet come in. Also, for children who are new SSI applicants, usually there has been only a month skipped between application and the first payment received, but now it is taking 6 to 7 months to get the first check. This was described by the administrator we interviewed as a temporary issue that will be resolved as the SSA office works through the immediate caseloads.

The administrator we interviewed identified one problem that became more difficult to resolve when the SSA district office became backlogged. The Home notifies SSA whenever a child is discharged, so that SSA can follow up to make sure that the correct payment is going to the family. The personal care provided by the Home is at the highest payment level for SSI, at about \$615, while in the family home, the child would receive about \$480 at most. If the representative payee form does not go through, the parent may be keeping these payments. There also are some situations in which parents collect the SSI benefit while the child is in the facility rather than turning it over. Normally it is a

simple process to transfer the representative payee status from the parent to the Home, but the backlog has prevented it from going smoothly in all cases.

Given their overwhelming caseload, the administrator suggested that SSA may not have the resources to pursue parents who are continuing to receive SSI payments after the child has been admitted to the home. The effect is that local agencies (Mental Health, FIA, the court system) would have to make up the costs of what could be covered through SSI payments. The Children's Home will be reimbursed whichever funding stream is used, and thus it would only be the other agencies that might feel the financial impact.

There are other effects on public agencies that provide referrals to the Children's Home as well. There are two campuses in the Children's Home; one campus takes care of the less impaired children, and the second more intensive campus takes care of children with the most severe impairments, at almost a one staff to one child ratio. One campus daily rate is around \$100, and the other campus is around \$200 per day. This is what the Home bills the mental health agency. If a child is receiving SSI, the bill to mental health will deduct the SSI payment from the total bill. If the child is not receiving SSI at the home, then the full bill goes to the county agency, and thus there is a county vs. federal funding trade-off.

A final issue raised by the administrator was that the \$15 fee given to providers for costs related to redeterminations has been disallowed since 1996. This is not a large cash flow issue but did help cover some of these costs for the facility.

### ***Observations of Family Impact***

The administrator we interviewed stated that SSI recipient status does not change the services provided to a child in the Children's Home. Also, children's Medicaid enrollment has not been affected by the SSI policy changes. One concern for the Children's Home is the automatic enrollment of children in PHPs; the facility cannot take all children to different primary care providers and thus prefers fee-for-service payment arrangements for children in residence. The mandatory enrollment in PHPs is waived for these children but some problems are occurring in FIA with respect to this waiver process. This is not related to the SSI policy changes, however.

## **7.5 SUMMARY OF FAMILY INTERVIEWS**

We interviewed nine families in Detroit during the week of August 31, 1998. Parents of these children stated that their children had the following diagnoses when they began receiving SSI: hearing deficit and learning disability; Tourette's Syndrome and ADHD/behavior problem; ADHD and learning problem; emotional problem; ADHD, asthma, and emotional problem; learning problems and enuresis; learning problem; asthma and seizures; learning problem, behavior problem, and delayed motor development.

Six of the nine families had appealed the cessation of SSI benefits either at the initial cessation or later in the process. Of the six families who appealed, four had requested benefit continuation. Three of the four families were continuing to receive benefits at the time of the interview.

### **7.5.1 Experiences with the Redetermination Process**

#### ***Understanding of the Redetermination Process***

All of the parents felt they understood the letters and other information they received from SSA about the new eligibility requirements and the redetermination process. One parent said she did not get information on an ongoing basis from SSA and instead relied on a relative who seemed to understand the process. When asked if there was anything about the process that they had not understood, several parents expressed confusion about what information SSA was considering in re-evaluating their child's eligibility. For some parents, this was partly because they did not know specifically why their child initially had been found eligible for SSI; these parents mentioned several medical or other diagnoses but were not able to state what diagnoses/conditions/problems contributed to the child's eligibility. A number of parents said that their visits to the SSA office for medical assessments or for hearings did not seem to focus on the child's underlying problem. One parent said that the child had cognitive tests ("games") when his problems were medical and emotional in nature, and did not understand why the assessment had focused on cognition.

#### ***Appeals and Benefit Continuation Requests***

Of the three parents who did not appeal, two parents had not appealed the child's case when the cessation information was received because they thought the child just couldn't get SSI anymore after welfare reform. One of these two parents who did not initially appeal, in part because she lost the SSA letter, reported that she did contact the SSA district office approximately three months later and was allowed to appeal at that time. The third parent who did not appeal said that while the letter might have said something about an option to appeal, no one talked to her about it, and she figured that SSA knew best about whether the child was eligible or not. Around the same time, this parent also received a letter stating that she owed SSA \$12,000 and this further discouraged her from pursuing the child's eligibility (she had not heard within the past year whether the \$12,000 was a mistake or whether she was expected to pay any part of it).

Among the six parents who had appealed, the common reason for appealing was that the child continued to have a disability and thus deserved both the SSI income and the Medicaid benefits that came along with receiving SSI.

One parent offered a perspective as someone who had no intention of appealing but was being repeatedly contacted by SSA. This view came from a parent who said that in

Summer 1998, she had started to receive continuing phone calls from SSA - possibly from Lansing - to encourage her to appeal; she had asked that she not be called anymore, although the calls were continuing to come. This parent had not appealed because her child no longer had the medical problem that was the original reason for receiving SSI, and because it was too much of a “hassle” to go through the process. She did not understand why she would now be pressed to appeal the case after her child’s SSI benefits were cut off so quickly in the first place.

Four of the six parents who appealed had requested benefit continuation during the appeal because they needed the income. Another one of the six parents appeared not to know that benefit continuation was an option. Finally, one parent who appealed but did not request benefit continuation during the appeal said that she was currently having to pay back some of her child’s SSI income because of a work income fluctuation (her actual income differed from her expected income used to calculate the SSI benefit). This experience made her unwilling to request continuing benefits because she wanted to avoid having to pay back more money, and knew from the initial cessation letter that she would have to pay back benefits received during the appeal if the final decision was unfavorable.

Of those parents who requested benefit continuation, one parent believed that he had requested continuation of benefits for the child but that the SSI benefits had not started up again after being terminated. Another parent had received benefits during the first appeal period but believed she could not receive benefits after the second cessation, and was not receiving the income.

One parent stated in the interview that she felt she was discouraged from getting a lawyer when she first called the SSA office after receiving a general letter informing SSI beneficiaries about welfare reform.

## **7.5.2 Impact on Medicaid and Health Care Access**

### ***Medicaid Eligibility and Enrollment***

Two families reported that Medicaid eligibility had been lost after SSI payments stopped. One parent, who had a child with ADHD and emotional disturbance (and hearing/speech problems), had gone through a complicated employment change to insure her child after losing his SSI income and thus Medicaid coverage. The parent initially reduced her hours as manager of a restaurant so she could take on a job that provided health benefits. Both of her children were uninsured for a six month period while the parent tried to increase her working hours at the second job so that she would be eligible for full benefits, which had just occurred in August 1998. Her husband worked at the same restaurant that did not provide any health benefits.

The second family stated that the loss of SSI had affected the child’s Medicaid coverage in a way that restricted the child’s access to some of the extra benefits that Medicaid provides. This one parent whose child lost SSI benefits in Fall 1997 reported receiving a letter from the Family Independence Agency stating that her child’s Medicaid

was affected, in Winter 1998, and reported that the child's Medicaid coverage ended in Winter 1998 also. The child has had coverage through the parent's work, but this coverage does not include the vision benefits that Medicaid covered. The child wore glasses but does not wear them now. This child had been enrolled in a PHP since he first received SSI in 1995. This parent reported using the Medicaid benefit only for health care needs that were related to the child's SSI—such as an emergency room visit when she thought the child was hallucinating at night—although the health plan subsequently would not pay for it. He receives his other health care through his mother's employment insurance.

One parent said that SSA letters told her the child's Medicaid would cease if SSI benefits were terminated. Several parents said that if their child lost the Medicaid eligibility that was linked to receiving SSI, they did not know of any other Medicaid or public health insurance options for their children.

### ***Transitions to Prepaid Health Plans***

Only one of the seven parents whose child's Medicaid eligibility had continued reported that she expected to have to switch the child from fee-for-service ("straight") Medicaid to a PHP.

### ***Access to Medical and Mental Health Services***

Several parents raised difficulties with access to services that they had experienced or had anticipated due to Medicaid-related issues. One parent who had increased her working hours to 70 hours per week said that while the private health insurance she had obtained was important to her children, she had been able to work out an arrangement with a counselor her child was seeing to continue seeing the child at \$2 per visit. She was not willing to use mental health services through her new private health plan coverage for her child because she did not want to disrupt the child's relationship with the local child mental health clinic and the counselor. Additionally, she did not want to take her child to visit a mental health professional, covered under her benefits, because this provider was a significant distance from her home.

Another parent said she had been told by her FIA social services caseworker that a switch to a Medicaid PHP would result in loss of the pharmaceutical benefit that covered the child's medication.

The two parents whose children had ADHD said that they had refused to allow the child to receive Ritalin. One of the parents said that she had heard about side effects of Ritalin and did not want her child to experience any more health problems than he already had. The other one parent said that she did not trust the general practice physician who took care of her child to prescribe Ritalin because he did not have the necessary expertise to take care of a mental health or psychological problem.

### **7.5.3 Socioeconomic Impact**

#### ***Total Family Income***

Total family income was reported to not change significantly in three of the nine families. For two of these three families, total income had not changed because they requested had benefit continuation and were still receiving monthly SSI payments for the child. In one family, the total household income had remained nearly at the same level after SSI payments ceased because the child was added to the ADC grant and the mother had started a job. All of the parents who had lost SSI benefits for their child reported lower incomes relative to the period when they had last received SSI.

#### ***Work Participation***

The majority of the parents we interviewed had gone back to work or had increased their working hours in response to the loss of SSI income. Two of the nine parents themselves continued to be recipients of SSI. Two of the nine parents were grandmothers of the child; one of these two grandparents received a retirement pension, and one received SSI. Of the remaining six parents, two had increased their working hours, one did not increase working hours because of her children, and two had entered the workforce after the SSI stopped, and one continued to rely on public assistance.

One parent who found a second job that provided health benefits had increased her working hours from 40 hours per week at her first job, to 70 hours total at two jobs (30 hours at her first job, and 40 hours at the new job that provided health benefits). Her husband had continued to work full time, and their total income was still lower than it was when they were receiving SSI benefits for the child.

#### ***Use of Public Assistance***

Two of the four families with an AFDC/TANF cash grant at the time had added the child who lost SSI benefits to their AFDC/TANF grant. One family planned to apply for a new AFDC/TANF cash grant. None of the families had newly applied for Food Stamps. Total Food Stamps had declined for one family since SSI benefits had stopped, and one family planned to apply for Food Stamps. At least one parent, who was receiving cash assistance for her four young children (including the child who lost SSI benefits), expressed concern that even though she was working full-time it would be difficult to make ends meet when the public assistance stopped as part of Michigan's new time limits.

Excluding the two families in which the grandparent was the child's guardian, five of the seven households were single parent households. One of these five families with only one parent in the household was receiving child support for the child.

One parent said that she had gone to the Family Independence Agency requesting income assistance for her family. She told them that the child's SSI payment was used for

him, and was not used as part of her family's general income, but she was informed that this counted as total family income, and she was not eligible.

Another parent visited her social services caseworker after her child lost SSI. The parent reported that the caseworker required her to add this child to her AFDC/TANF grant, although the parent stated to the caseworker that the child's father provided informal support to her, and that she did not want this particular child to be added to the grant. The parent reported being told by the caseworker that public cash assistance and Medicaid for others in the household (a child and grandchild) would be threatened with termination if the former SSI recipient child were not put onto the cash grant. According to this parent, subsequently the FIA required the father to provide child support and took some money out of the father's contribution, which the mother described as resulting in less net income coming to the child and the household overall.

#### **7.5.4 Caregiving and Other Child Impact**

##### ***Living Arrangements***

One interviewed payee was a grandmother who had temporary custody of four children under age 15, two of whom had been receiving SSI. This parent was paying very low rent for a house that she said was too small given the family size. The grandmother did not report any income related to the children's out-of-home placement status, nor mention this as a potential income source. The grandmother said that she planned to request permanent custody in the near future because her daughter would never be able to take custody again, but that to maintain custody she needed extra resources to make sure that the household was adequately maintained for the children. She expressed concern that she would be able to maintain a household that met the court requirements given the children's problems and the income loss. She also stated that loss of SSI income would force her to move in with her mother, who did not have space for the four children, which would mean placing her four grandchildren into non-kinship foster care.

None of the children or families had moved since the child's SSI was initially affected.

##### ***Child Care***

Several parents expressed concern and hesitancy about placing their children in non-kinship day care arrangements. Those who had child care for their children were using kinship care (usually a grandmother and in one case an aunt). Generally parents said in the interviews that they would not trust a day care center or a someone who was not a personal friend or relative with their child, but did not link this decision to the child's disability or any special caretaking needs. One parent either paid her mother-in-law to care for the children (ages 8 and 9 years) or else took them to work with her, especially in her last job at a fast food restaurant. One parent had started a full-time job as part of the



welfare reform work requirements but took the summer off because her designated babysitter (a relative) was unwilling to be available on a full-time basis.

### ***Other Child Impact***

Two parents stated that they wished that the lost income could be replaced with assistance in finding the services they needed for their children. One parent felt that her child had received more help in school when he was receiving SSI, but that now she was on her own in finding help for him. Another parent has asked the SSA district office for help in finding a therapist and said that she did not know where to find a therapist or how to find help in searching for a therapist.

Several parents discussed the stress that the child's problem(s) placed on the family. One parent of a child with learning disabilities reported that she could no longer afford to pay for private school for the child, and the child had started in public school in the 1998-99 school year. The child was no longer receiving the one-on-one teacher attention that he had received in the private school. This parent was concerned that the child's learning disabilities were now more obvious to other children and teachers in the public school and were creating a stigma for the child, whereas in the private school, there was individual attention to children, and thus the child had not suffered from this stigma. This parent also described her frustration in working with her child (who has a learning disability), and said that both she and the child became upset when they worked together, even though she knew that the child's problems were not the child's fault. She was relying on the child's grandmother to help the child with schoolwork because the grandmother had more patience.

## **8. SUMMARY OF FINDINGS ACROSS CASE STUDY SITES**

This section describes the findings from the agency and family interviews, and synthesizes these findings with respect to the policy contexts in each site. In presenting this integrated perspective, it is important to keep in mind the caveats about the case study methodology discussed in Section 2. The results of the interviews are not intended to be statistically representative within each case study sites, across case study sites, or for the country as a whole. Thus although we present some summary statistics for the family interviews in particular, the resulting percentages should not be interpreted as providing local or national averages, or as offering conclusions about the perceptions and experiences of the families or communities overall.

Despite this limitation on statistical representativeness, we believe there are some broader inferences that can be made by comparing findings across case study sites. The experiences reported by families and by agencies and providers are included within the likely range and nature of experiences that would be seen for a statistically representative sample of agencies or families. As a result, these perceptions and experiences are useful for generating hypotheses that can be tested in the complementary quantitative analyses. The outcomes observed in the case study sites (including how families and agencies responded to welfare reform) provide insight into how other communities and States may have responded to and been affected by welfare reform, based on different characteristics of their policy environments. Thus, in drawing these broader conclusions, we endeavor to account for the differing policy environments across the states, and the differential implementation approaches adopted across the sites we visited.

Our discussion proceeds first by focusing on the agency and provider interviews, and then on the family interviews.

### **8.1 SUMMARY OF FINDINGS FROM AGENCY/PROVIDER INTERVIEWS**

This section first describes the reported impact of the policy change on SSA and DDS agencies, and then provides a summary of how agencies other than SSA reported having been affected. This is followed by a summary of the perspectives offered from the individuals we interviewed in SSA offices and in other agencies regarding the impact on SSI beneficiaries, including observed as well as anticipated effects.

#### **8.1.1 Impact on SSA Regional and Field Offices**

##### ***SSA's Implementation of the Redetermination Process***

Most SSA staff we interviewed stated that the initial effort to complete the redetermination of childhood disability cases caused scrambling among staff to meet time targets. In general, in the offices we visited, SSA staff at all levels reported feeling short-

staffed for activities ranging from the development of policies and procedures guiding the local processes, to the efforts to contact families. Some DDS staff reported feeling pressure to achieve certain targets in redetermination outcomes without clear guidance in how to achieve these targets.

### ***SSA's Implementation of the Re-Reviews (Commissioner's Top-to-Bottom Review)***

The re-reviews stimulated a complex process of case review and tracking that was difficult to implement. Some SSA offices reported that there were not enough resources in the policy division at SSA Headquarters to generate highly refined policies and procedures when the re-reviews were first implemented, and felt that this lack of resources caused local delays in interpreting rules and confusion during the initial implementation. The SSA staff we interviewed also identified some benefits of the re-reviews, such as the fact that the re-reviews often enabled the procedures to be very refined and accurate through close monitoring and attention to detail. The politicization of the redetermination process that some staff perceived, and the ongoing involvement of advocacy groups, also helped to refine the policies and procedures in a way that ultimately aided in the implementation, although this attention also produced pressures on staff as well as on the affected families.

### ***SSA's Implementation of the Dedicated Accounts Policy***

The new dedicated accounts policy, while distinct from welfare reform SSI changes, was identified as a significant implementation issue by SSA district offices. This policy—which requires that lump sum payments that exceed a specified amount be paid directly to a family's bank account and that recipients be instructed to use these funds for goods and services related to the child's disability—affected those families who received lump sum payments when a cessation was overturned on appeal. While the intent of this legislatively-imposed provision was clearly identified by the SSA staff who raised it as an effort to target funds to helping the child directly, the policy has been difficult to implement. Specific reasons mentioned by staff include the lack of clear guidelines, the individual judgment that is required, the staff time that is required, the difficulty of establishing a new role for personnel given other changes underway, and the public relations challenges (i.e., interactions between SSA field office staff and families) that accompany this new role.

## **8.1.2 Impact on Other Agencies and Providers**

### ***Handling Medicaid Eligibility for Children***

Administrators who were interviewed from the State Medicaid agencies perceived that most of the affected children should not have lost Medicaid eligibility. None of the administrators had observed any declining Medicaid enrollment figures that would indicate that children were losing coverage, or knew specifically of any significant coverage losses for the affected children. Several states, such as Connecticut and Louisiana, have

procedures in place to track children who were receiving SSI and then moved to the state's TANF program. In general, the states with SSI-linked Medicaid eligibility were not fully prepared to implement the specific "grandfathering" provisions of the 1997 BBA.

While administrators in the state Medicaid agencies generally felt there were no systematic reasons that a large number of affected children would lose Medicaid, several ways were identified by which children could lose Medicaid coverage in each of the states, particularly those children whose SSI eligibility was determined earlier in the process. For example, although Louisiana has a comprehensive Medicaid eligibility redetermination process in place, if parents never responded to the Medicaid program's requests for information about their SSI appeal, employment status, etc. then the child could lose eligibility.

For children age 18, several Medicaid agency administrators stated that losses in Medicaid eligibility are possible due to limits in state Medicaid program coverage for individuals over age 18.

### ***Maintaining Eligibility for Children in Protective Custody***

Administrators interviewed in child welfare agencies reported that they were generally able to keep up with the SSI eligibility redetermination process for children in protective custody. One local child welfare agency reported using a special health care program established for children in foster care to provide the necessary medical evidence for children's redeterminations. Several of the SSA offices described the special efforts they had made to keep records updated for children in foster care and to coordinate with child welfare agencies, to prevent these children from falling from the rolls. Sometimes this involved proactive work by SSA staff to apprise social workers of information needed for the redetermination process, and also involved flexibility by SSA staff in granting good cause for late appeals.

### ***Response by Title V Children with Special Health Needs Programs***

Most Title V programs reported that they had not been affected and had not observed a significant impact on their populations. All of the programs reported that they were continuing their roles as a referring agency to SSA for children with medically eligible diagnoses.

### ***Impact on Other Public and Private Social Service Providers***

Aside from the Medicaid program and other public health insurance programs for low income children, other public and private sector social service providers whom we interviewed typically did not attribute significant changes in their own programs or populations served to the 1996 SSI benefit changes. In many cases, the agency or service provider engaged in activities to plan for the changes and coordinate with other agencies,

but the anticipated impact had not materialized by the time of our site visit. This result was particularly salient for the legal assistance providers we interviewed.

### **8.1.3 Observations on Family Response and Impact**

#### ***Beneficiary Appeals and Requests for Benefit Continuation***

Most SSA staff we interviewed felt that many families who did not appeal initially had understood the eligibility change and believed that their child no longer qualified for SSI. Some SSA staff felt that ongoing efforts with many of the “failure to cooperate” cases were contributing to a public relations problems with families that was not helping the agency.

#### ***Observations on Beneficiary Responses***

Some SSA staff reported that families seemed more interested than they had been in the past in how to get and maintain jobs. Many families were thought to be turning to public assistance at least as a temporary step to replace the lost income. It was recognized that not all families would be able to turn to public assistance, however, due to upcoming time limit provisions. Moreover, in one state it was mentioned that families who lose AFDC/TANF due to time limits can then immediately lose most or all SSI benefits, due to the way that work income is counted. When a family is receiving public assistance, then SSA does not count their work income again in calculating the SSI benefit.

#### ***Observations on Beneficiary Impact***

Administrators and staff interviewed in a number of agencies perceived that many families were using the SSI income for basic family needs rather than specifically for the child’s disability or health needs, and thus the loss of the SSI was causing household income stress but was not necessarily affecting the child’s access to health or mental health services specifically.

In terms of special populations, the administrators we interviewed in agencies such as the Title V Children with Special Health Care Needs programs, child welfare agencies, and programs for children with mental retardation or developmental disabilities, have not yet perceived a significant impact on the populations they serve. For the most part, children in foster care were thought by those we interviewed to be unaffected, largely because of the special efforts undertaken by SSA offices and by child welfare agencies to protect children’s eligibility by timely appeals and production of medical evidence. There was some evidence in at least one site that high SSA workloads had temporarily slowed the processing of new child SSI applications, including institutionalized children, causing some delays in income streams and local/state financial impact.

Agency administrators raised both future sources of income and access to Medicaid coverage as potential concerns for those children reaching age 18.

### ***Observations on Medicaid Enrollment***

A number of agency administrators and providers we interviewed stated that they had anticipated more Medicaid eligibility problems for affected children than were generally observed or heard about so far. Some felt that the Medicaid problems were sporadic rather than systematic, and consequently the decline in attention to the issue made those families who were experiencing problems less visible. A number of administrators and providers reported the concern that some children's Medicaid eligibility would lapse not because of a state's eligibility restrictions but because of the responsibility placed on families to retain or restore the coverage, or to pursue eligibility alternatives. Most agencies raised concerns about whether families would follow through with the local social services office when Medicaid eligibility was lost due to SSI eligibility changes. Coverage for those children reaching age 18 was identified as a potential concern by a number of agency administrators.

In most states, it was not yet clear how the grandfathering provision would be handled by Medicaid and disability determination agencies. Most agencies perceived that Medicaid eligibility and enrollment was not a major issue due to broadening eligibility and due to temporary policies that were put in place to maintain Medicaid eligibility for children affected by the SSI policy change.

## **8.2 SUMMARY OF FINDINGS FROM FAMILY INTERVIEWS**

This section describes findings from our interviews with parents regarding their reported experiences with the eligibility redetermination process, their responses to the potential loss of SSI income, and their perceptions of the impact on the child and their family. In addition, we discuss whether there are noticeable patterns in family outcomes associated with differences in the state-level policy environment.

In order to provide a benchmark from which to synthesize the results, Table 8.1 provides a summary tabulation of the characteristics of the families interviewed, including the family composition and work participation prior to the SSI eligibility changes. The results are presented with the range of responses across sites (minimum, maximum, and mode across sites) with percentage distributions show for the totals. Table 8.2 provides a further summary of the findings with respect to key evaluation questions from the family interviews. The outcomes in Table 8.2 focus on how families reported that they had been affected by and have responded to the eligibility changes. These outcomes are highlighted in greater detail in the discussion that follows. As we have noted earlier, these summaries should not be interpreted as characterizing a statistically representative sample of families and affected children. Rather, they serve to characterize the potential range of experiences as a result of the welfare reforms.

**Table 8.1**  
**Summary of Family Characteristics and Range in Characteristics Across Sites**

	Range		Mode	Total	
	Minimum	Maximum		No.	%
Total interviews				44	
Family Composition					
Single parent family	5	10	5, 6	32	73
Two parent family	0	4	0	6	14
Grandparent/kinship foster care	0	2	2	6	14
Use of Public Income Assistance					
Families with > 1 child SSI recipient	0	3	1, 3	8	18
Families receiving any non-SSI income assistance prior to SSI change	3	5	3, 5	22	50
Families receiving other SSI only prior to SSI change	1	2	1	6	14
Family Work Participation					
Parent(s) not in workforce due to disability or elderly age	1	3	1, 2	9	20
Parent(s) eligible for workforce (non-disabled/non-elderly)	6	8	6, 8	35	80
Parent(s) working prior to SSI change	3	7	3	20	45

### **8.2.1 Experiences with the Eligibility Change and Redetermination**

#### ***Redetermination Process***

Most families stated that they understood the initial letters from SSA about welfare reform, the redeterminations that were beginning, and their option to appeal. Many families expressed confusion about how the appeals process worked and what the implications of requesting benefit continuation were. In a few instances, some of the difficulty could be attributed to language barriers although in other cases, non-English speaking parents stated that they had ready access to translators and translated materials. Most of the families who were non-English speaking reported that they were able to understand materials and that not having English proficiency did not adversely affect their understanding of the redetermination process.

**Table 8.2**  
**Summary of Family Impact and Range of Responses Across Sites**

	Range		Mode	Totals	
	Minimum	Maximum		No.	%
Total interviews				44	
Redetermination Experiences					
Appealed	4	8	6	29	66
Requested benefit continuation	1	5	3	15	52
Sought/seeking legal assistance	0	1	0	2	5
Medicaid and Health Care Access					
Ever lost Medicaid	2	3	2	11	25
Ever lost Medicaid and not restored	1	2	1	6	14
Switched/anticipate switch to prepaid health plan (PHP)	0	2	0, 2	5	11
Medicaid/SSI loss impaired access	1	3	2, 3	11	25
Switched to private insurance	0	1	0	1	2
Socioeconomic Impact					
Decline in family income	4	8	5	28	64
Increase in use of public assistance	2	3	2	11	25
Parent(s) eligible for workforce (non-disabled/non-elderly)	6	8	6, 8	35	80
Parent(s) currently working	5	8	5	29	83
Parent(s) who increased working hours or took new job	1	4	2, 3	13	37
Living Arrangements					
Family has moved	0	4	4	11	25
Change in custody/caregiver	0	1	0	2	4

Overall, about two-thirds of the families interviewed reported that they had appealed an initial cessation decision, and about half of those that appealed stated that they had requested benefit continuation. The decision to appeal initially was often reported to be related to the perceived chances of overturning the cessation decision, although in



several cases, the lack of an appeal was related to idiosyncratic factors (e.g., a parent who was ill or missed the deadline for other reasons). Consequently, a number of families did take advantage of the opportunity to appeal following the "good news" letter. The decision to continue benefits was usually linked by the interviewee to whether or not a family was willing to take the risk that benefits might need to be repaid.

### ***Family Use of Legal Assistance***

Few families stated that they had accessed legal assistance. Several of the families whose children's cases were nearing the ALJ level of appeal stated that they were considering seeking legal assistance. The one parent who said that she sought legal representation during the appeals process did not have her case accepted by the legal aid organization that reviewed her child's case.

## **8.2.2 Impact on Medicaid and Health Care Access**

### ***Medicaid Eligibility and Enrollment***

A number of parents reported problems with retaining Medicaid coverage for their child(ren) who lost SSI. About one-fourth of the children had lost Medicaid eligibility (becoming disenrolled) for some period of time following the SSI eligibility changes. The proportion of children losing Medicaid ranged from 2 in one site to 3 in another site..

Some parents stated that the source of the problem was that information supplied by welfare caseworkers was inconsistent with information from SSA claims representatives. Several parents who appealed their child's cessation of SSI benefits reported being told by their welfare caseworker that SSA was responsible for the child's Medicaid coverage during the appeal. Conversely, they reported being told by staff in the SSA field office that the welfare/social services caseworker was responsible for Medicaid coverage issues. This resulted in some parents going from the welfare caseworker to the SSA office, getting different information, and giving up before the eligibility issues were resolved.

Parents who recalled receiving information about what might happen to their child's Medicaid eligibility either recalled letters stating that they children might still qualify for Medicaid through a different eligibility category, or recalled being told by SSA district staff that the Medicaid coverage would not be affected. Several parents were unsure of whether their child was still covered by Medicaid or whether coverage had been terminated.

For 6 of the 11 children who lost Medicaid, families reported that the coverage had not been restored at the time of the interview. Three of these six children who have not had Medicaid restored (one each in three of the states we visited) turned 18 in the past year. The other half of this group comprises children under 18 years of age (one each in three of the states we visited). Of the children under 18 who have not had Medicaid restored, two of the three had not appealed the SSI cessation (the third appealed early in

1998). Some or all of these three children may not have met poverty-related group Medicaid eligibility. Total household income was reported to have declined for all families who had lost SSI, and none of these families reported having AFDC/TANF cash grants.

### ***Transitions to Prepaid Health Plans***

Several parents stated that their child had been enrolled in a managed care plan since losing SSI, or that they were anticipating a change from Medicaid fee-for-service to managed care that would result in their child's loss of coverage for prescription medications. Families affected by such switches ranged from none in two sites to 2 families in another two sites. Several parents reported that their children were going without over-the-counter or prescribed medications due to the cost.

Several parents of Medicaid-covered as well as now privately insured children reported distrusting the mental health provider(s) that contracted with their managed care plan. Some of the reasons given by these families for not utilizing the contracted provider included: mistrust because the provider was not a pediatric specialist, the physical distance to the provider, or the fact that the child did not know the provider and it would require re-establishing a therapeutic relationship with the child. One parent continued to pay what she could afford to a local mental health clinic because she could not transport her child to the mental health provider that the health plan would allow.

### ***Access to Non-Medicaid Health Insurance Coverage***

Across the five sites, only one family reported that they had restored health coverage for the child by taking a new job that provided commercial health insurance benefits. A very small number of families across the sites said that they knew of their State's SCHIP program as a possible insurance option if Medicaid eligibility was lost.

### ***Access to Medical and Mental Health Services***

Parents in approximately one-fourth of the interviewed families stated that their child had lost Medicaid and/or SSI benefits and further felt that this loss had impaired the child's access to medical and/or to mental health services. The proportion of families who felt that the loss of SSI income either directly, or indirectly through effects on Medicaid coverage, affected access to services ranged from one to three of the families in each of the sites. Many more of the parents we interviewed reported having significant difficulty finding the necessary services for their children, whether or not they were continuing to receive SSI income. Families in each of the sites raised this issue. The most commonly reported difficulty was lack of knowledge in how to go about finding an appropriate provider for the child's mental health needs.

For about half of children with an ADHD/ADD diagnosis, the parent reported not wanting the child to receive Ritalin. Three parents were concerned about side effects or overall effects on the child's normal development, and two parents stated more specifically

that they would not allow their child's current provider to manage a Ritalin prescription (e.g., the child's current provider was not a pediatrician, or was not a psychiatrist). Another parent stated that she could not communicate with her child's psychiatrist due to a language barrier and thus had not acted on this recent diagnosis.

### **8.2.3 Socioeconomic Impact**

#### ***Economic Impact***

Family income was reported as having declined in most families whose SSI benefits were ceased. The proportion of families reporting a decline in total ranged from half of the families in one site where 5 of the 10 families requested benefit continuation and in another site where 3 of 7 working age families increased working hours or took new jobs, to all but one family in a third site (where 7 of 8 working-age parents already were in the workforce prior to the SSI changes). Some families temporarily increased total income by requesting SSI benefit continuation during appeal, at the same time that they sought other public assistance. Many families said they had turned to public assistance following the loss of SSI income. Of these families, most turned to welfare and Food Stamps programs to compensate partially for the income loss. Several parents stated that in response to welfare reform, they tried to access child support payments from absent fathers.

#### ***Response to the Potential Income Loss***

Particularly in states that were further along in implementing welfare reform and associated time limits for public assistance, such as Connecticut and Michigan, parents were returning to or newly entering the work force. Current work participation among families (excluding elderly guardians and parents with disabilities) ranged from 100 percent in one site and all but one family in three other sites, to 5 of 8 in the fifth site. Most families that already were receiving an AFDC/TANF cash grant reported adding the child to the existing cash grant. A few families were reaching their time limits for cash assistance but had not yet been affected by this income loss. Other families were turning to Food Stamps or emergency assistance. Several families had begun to receive child support payments or were now seeking support from absent fathers.

#### ***Work Participation***

Among those available for work, somewhat less than half of all families reported that they had entered the workforce or increased their working hours. Several families quit jobs or reduced working hours due to the demands placed on their time by their children, however. Several parents reported that they were unable to work or were having difficulty working at the same time that they were meeting the child's needs, because they had to be available when problems occurred at school.

## **8.2.4 Caregiving and Other Child Impact**

### ***Living Arrangements***

As described in Section 2, we interviewed several foster parents who were *payees* for a child SSI beneficiary, but we generally excluded from our sample any children who entered foster out-of-home placements *following the loss of SSI*, or who continued to be in foster care and had an *agency payee*.

All of the caretakers we interviewed of children in foster care were relatives of the child(ren) in their care. Two of the six foster caretakers, all of whom were grandparents or great-grandparents of the child, expressed concern that they would not be able to continue caring for the children due to the income stress. We also interviewed one parent who was paying child support for the child, who entered a foster placement shortly after losing SSI. This parent reported that taking a job with extended, swing shift hours in response to the income loss, and not being able to access family therapy because their family income exceeded eligibility thresholds for programs she had contacted, were factors that contributed to the child's entry into foster care.

About one-quarter of the families had moved since losing the SSI income, with several of these families attributing the move to income loss and several stating that they had moved for other reasons. One family became homeless after losing the child's SSI income but at the time of the interview was living in a home due to assistance from a church member.

### ***Child Care***

Nearly all parents with young children reported that they relied on a family member or personal friend to provide childcare rather than a child care/daycare center. Parents with young children who were newly entering the work force generally reported that they were receiving childcare subsidies through public assistance programs. Several parents of older children had difficulty maintaining their jobs, or with continuing their school studies, because they had to be available to bring their child home from school for behavior problems, and had no one they could rely on to do this. This was also raised as a problem for after school supervision, by several parents who felt that grandparents or friends whom they would rely on for child care were unable to manage the child's behavior problems or other special needs and thus that the parent had to be available.

### ***Other Child Impact***

Several parents pointed to the child's schooling as the primary impact of losing or potentially losing SSI. The two children who were in private schools are now enrolled in public schools following the loss of SSI income. Parents of these children The parent of one of these children felt this might harm the child's physical health, and the parent of the other child felt this would harm the child's school performance. Both children had just started in the new schools so there had not been an opportunity to observe any impact.

Nearly all parents stated that their child's overall health, functional status, and school performance had remained the same or had improved since the notification about their child's SSI eligibility redetermination. Among those children whose physical or mental health status had remained the same or declined, only a few parents felt that the income loss was a contributing factor to the child's health and functional status. These parents pointed to the inaccessibility of services for the child—medical care, mental health services, and/or family support—as the most significant contributing factor to their child's deterioration or failure to improve.

Particularly for the older children, it appeared that parents who were able to establish an ongoing relationship with a specific provider, or whose children had secured the interest and assistance of a particular teacher or school staff member, had been able to assemble a set of resources for the child that were improving the child's function and future prospects. For example, several such parents reported that their child's provider called periodically to check up on the child and family even after Medicaid coverage was lost or the parent could not continue paying out-of-pocket for continued visits. In contrast, several other parents (particularly of children with emotional/mental disorders) specifically stated that they were socially isolated or did not have access to support from family or friends, or stated that they were unaware of where they could even begin looking for help for their child's needs.

In the single rural site visited, several parents expressed concern about their older child's job prospects given specific physical disabilities and thus the children's difficulties with undertaking agricultural work.

## **8.2.5 Impact of State Policies on Child and Family Outcomes**

### ***Medicaid Eligibility and Enrollment***

Across the sites, administrators we interviewed in most agencies did not expect that Medicaid eligibility would have changed for many families by this point in the implementation process. Among the families we interviewed, the frequency of loss of Medicaid coverage after SSI benefit cessation or during an appeal did not appear to be related to the generosity of Medicaid eligibility across the five sites. Medicaid eligibility was lost for at least one child under age 18 years in each site. Based on our interviews with the Medicaid agencies across states, children whose cases were appealed, and who were under 18, should have remained Medicaid eligible and enrolled. Despite having a particularly systematic process for redetermining Medicaid eligibility under all possible groups when an individual's status changes, in Louisiana several families reported Medicaid eligibility losses just as families reported in the other states.

### ***Transitions to Medicaid Managed Care***

California was the only one of the four case study states in which the loss of SSI-linked Medicaid could move the child to mandated managed care enrollment group.

Particularly in Los Angeles County, agencies identified such enrollment changes as a likely outcome, and this was supported by findings from the family interviews. Mandatory transitions to prepaid health plans (PHPs) following SSI loss were more frequent in Los Angeles—where SSI-linked eligibility exempts children from mandatory PHP enrollment—and in Detroit, where SSI eligibility does not confer an exempt status but Medicaid managed care penetration is high—than in other locations.

### ***States' Title XXI (SCHIP) Child Health Insurance Expansions***

At this point in time, the program type and scope of eligibility for the states' SCHIP health insurance expansions did not appear to be having much effect. From the family interviews, there was little mention of transitions to Medicaid eligibility groups other than from SSI to TANF linked groups (although there could have been a seamless transition of which families were unaware). While agencies in the case study sites often raised the new SCHIP program as an alternative to Medicaid if lost (or as a reason for children's health insurance eligibility continuing for those states that only expanded their Medicaid program, such as Louisiana), only one of those parents who felt their child would lose (or had lost) Medicaid raised the SCHIP program as an option.

### ***States' Welfare Reform Provisions***

In the states with 24 month time limits for consecutive months receiving TANF benefits, and with earlier TANF start dates, it was expected that families might respond differently. This was confirmed by the family interview findings. Several parents still receiving TANF benefits in Michigan were anticipating, but had not yet been affected by, TANF time limits. In Connecticut, one family had lost SSI and also had lost TANF eligibility due to time limits, while another was receiving TANF benefits due to a six month extension granted to her. Because the TANF requirements and time limits were just beginning to take effect, and because most parents who were interviewed had already been working (or were working due to work requirements) in all states, it is not surprising that interviews did not reveal striking differences in family responses across the sites.

## **8.3 ISSUES FOR FUTURE STUDY**

The purpose of the first round of case studies was to explore the initial impact of the policy change on children and families, and to understand how SSA offices and other agencies responded. The first round was designed to identify some of the types of implementation issues and impact that may be expected as the policy change runs its course. Several questions were raised from the findings, and some of these questions are expected to be addressed in the second round of the case studies. The second round of case studies may determine how the concerns raised by parents and their expectations of impact are actually borne out, and also may identify some effects that were not initially anticipated by families. Overall, the perceptions and experiences reported in the first round of case studies have produced a range of possible hypotheses for further study in the quantitative analyses.

In terms of the redetermination process, it will be important to track access to and use of legal assistance/representation by families in the future. At least one legal advocacy group reported that they traditionally had not tended to encourage families to access legal assistance until a cessation had occurred. Initial patterns of legal assistance pursuit and access will be important to compare with patterns of use as families move further along in the appeals process.

Another question is what happens to Medicaid eligibility and enrollment for children who were receiving SSI at the time of the policy change. It will be important to sort out the effects on Medicaid enrollment once states are past the current turmoil of the initial implementation, and once a larger proportion of families move beyond the initial stages of the appeals process. In addition, by the second round of case studies, Medicaid provisions may be in place in those states that will require periodic disability determinations for the “grandfathered” cohort of children. This would make it possible to describe what procedures the agencies have put in place and how the families we interview are being affected.

As the policy implementation continues along with states’ broader welfare reform and Title XXI (SCHIP) changes, it would be informative to consider how state policy factors affect responses to and the effects of the policy change. States’ SCHIP programs may be implemented and advertised in all states by the time of the second round, and this would have provided families in some states with another opportunity to secure Medicaid coverage for the child.

Another key question is what happens to parent participation in the workforce and family income. Several of the families had just received notice of a second eligibility cessation several days before the interview, and a few of these parents reported that they now might have to try something different to make up for the income loss. As more families move further through the appeals process, there will be an opportunity to explore what plans families are making. Families may also be affected by changes in the economic environment, for example, if labor market prospects improve or deteriorate in the future. Also, families in several states may approach the new TANF time limits and thus lose this cash assistance and linked Medicaid eligibility. While children’s Medicaid coverage would not necessarily be jeopardized through the loss of TANF benefits, it should be possible to observe patterns in continual Medicaid enrollment for the affected children.

The longer run consequences for health insurance coverage, family labor market participation, and family income also have implications for the longer run health and well-being of affected children. In the second round of case studies, there will be an opportunity to determine if there are subsequent changes in children’s access to needed medical care, in the child’s health or functional status, and in other areas of functioning such as school or employment, for the responding families.

Because the case studies were designed to explore the types of effects experienced by families and agencies, and to inform the quantitative analyses, a number of important policy impact questions will require other data. For example, we purposely selected sites

with high numbers of affected children. While we did visit one site with a significant rural population and interviewed families in rural locations, most of the interviews were conducted in large urban areas. It would be important to know how families in low density, rural communities are affected, and also how the policy effects differ for families in large urban areas that have lower volume and proportion of child SSI beneficiaries.

Finally, the study design was limited by the sampling rules and by our inability to contact a significant proportion of the families due to out-of-date contact information. We do not know how the families who did not respond differed from those who did respond in terms of important outcomes such as the experience with the redetermination process and the impact of language or other barriers; changes in living arrangements or child entry into foster care; changes in family income and labor force participation; and so on. The case studies were intended to raise targeted questions about these possible effects rather than to provide an assessment of their impact, and thus some of these issues will be explored further through the quantitative components of the evaluation.





## **APPENDIX**

### **OVERVIEW AND CHRONOLOGY OF REDETERMINATION PROCESS**

This appendix describes the SSI disability determination process resulting from the 1996 welfare reform changes and the subsequent review procedures put in place following the Balanced Budget Act of 1997 and the Commissioner's Top-to-Bottom review in Fall 1997.

#### **A.1 REDETERMINATION PROCESS FOLLOWING PRWORA**

SSA began with a total redetermination workload of 288,000 childhood cases based on the universe of children receiving SSI as of August 1996 as identified from the Universe File. Of that group, 23,658 cases were continued prior to notices being sent because a paper review of their files determined that they met the eligibility criteria under the new law. The remaining 264,342 cases received notices by December 1996 that their benefits may be terminated following a redetermination of their disability status. Benefits for an additional 4,666 cases that were still under review when notices were sent were subsequently continued because they were found to meet the new criteria. This left a total of 259,676 cases to be redetermined.

The redetermination process begins with a review at the initial level. For cases that are ceased at the initial level, the process continues through a 60 day appeal period and upon appeal the case moves to a review at the reconsideration level. Ceased cases at the reconsideration level can be appealed next to an administrative law judge (ALJ). The third level of administrative appeal is the Appeal Council, and a final appeal is available through a civil action in federal district court.

**Initial Level.** At any point in time in the redetermination process, the 259,676 childhood disability cases subject to redetermination can be classified into the following outcomes at the initial level: (1) redetermined at the initial level and continued, (2) redetermined at the initial level and ceased, (3) terminated for non-disability reasons.

**60-Day Appeal Period.** For those cases that are ceased at the initial level, the child and/or the child's representative may appeal the decision within 60 days. The child's benefits may continue during the appeal period if requested within 10 days of the notice of cessation. The child or the child's representative is told that payments received following an appealed cessation decision that is ultimately affirmed should be repaid to SSA, but that this requirement may be waived following recipient request and SSA's evaluation of the recipient's circumstances. Of those cases that appeal, some elect to continue benefits during appeal and others do not.

**Reconsideration Level.** For those cases that appeal after the initial level, the cases are redetermined at the reconsideration level. This review is composed first of a case file review. If this does not result in a continuance, an opportunity for a face-to-face hearing

before a Disability Hearing Officer (DHO) is provided. These cases can be (1) redetermined at the reconsideration level and continued, or (2) redetermined at the reconsideration level and ceased.

**Subsequent Appeals and Reconsiderations.** For cases ceased at the reconsideration level, the child and the child's representative may pursue three more levels of appeals, with a disability determination decision following each appeal. The second appeal leads to a hearing before an ALJ, the third appeal is before the Appeals Council, and the final appeal requires filing a civil action in federal district court. Few of these higher-level appeals and reviews have been conducted to date for the cohort of children affected by the welfare reform legislation.

**Reapplications After Cessation.** Cases that are ceased as a result of the redetermination process may reapply for SSI benefits at a later date. In some cases, reapplicants will qualify because of a change in their disability status.

**Process for Age-18 Cases.** The redetermination process for the age-18 cases mirrors the process for the childhood cases, with the exception that no cases were screened out initially because they all are subject to redetermination regardless of diagnosis. The evaluation criteria differ from those used for childhood cases.

## **A.2 POLICY CHANGES FOLLOWING THE BALANCED BUDGET ACT OF 1997 AND THE COMMISSIONER'S 1997 TOP-TO-BOTTOM REVIEW**

The 1997 Balanced Budget Act (BBA) modified several aspects of the redetermination process for childhood cases. First, the BBA provided for the "grandfathering" of Medicaid eligibility for children subject to redetermination who lost SSI benefits. Other changes included extending the date by which SSA was to complete the disability redeterminations because of the PRWORA from August of 1997 to February of 1998 or when practical thereafter. In addition, the law provided that SSA may perform an age-18 redetermination within the one-year period following the child's 18th birthday or in lieu of a continuing disability review if SSA determines the case is subject to redetermination. The BBA also included a provision that allows SSA to determine that a continuing disability review (CDR) is not necessary at age one if the child has an impairment that is not expected to improve by that age.

SSA Commissioner Apfel initiated a "Top-to-Bottom" review of the implementation of the childhood disability redetermination process in Fall 1997. The report of the Commissioner in December 1997 identified concerns about the treatment of cases involving a diagnosis of mental retardation (MR), the accuracy of case processing across states and by impairment, and the exercising of appeal rights and benefit recontinuation requests when child cases were denied. Several case review policies and procedures were put into place pursuant to the Commissioner's Report.

**Reappeals and Benefit Continuation Renotification** The appeals and benefit continuation processes timeframes were extended. Specifically, children whose eligibility

was ceased as a result of the redetermination, and who did not appeal, were to be given a new 60-day period to appeal the decision, and a 10-day period to request benefit continuation. In addition, those who had appealed but had not requested benefit continuation were given a 10-day period to do so. The Reappeals and Benefit Continuation notices (also known as "good news" letters) included simplified language to ensure that parents understood their options. SSA sent both Spanish and English language notices to individuals who had not appealed initial determinations or did not request benefit continuation during appeal. These notices also included a list of toll-free telephone numbers so that individuals could obtain free legal advice. As of November 1, 1997, SSA had reviewed 235,000 cases resulting in approximately 141,300 cessation decisions, a 60 percent cessation rate. As of that date, 67,946 appeals requesting reconsideration had been initiated. Approximately 50 percent of cessation cases had not appealed and were eligible for re-opening.

**Review of Mental Retardation (MR) Cases.** SSA was to review all cases denied after redetermination that had a MR primary diagnosis code, and all initial applications with that code that were adjudicated after August 19, 1996 and denied. These cases were reviewed due to concerns about SSA's coding of impairments and concerns over whether redeterminations were being made correctly. In particular, when specific diagnosis codes were not available (e.g., a code for "learning disability" or "learning disorder" was not available until February 1994, while one for "borderline intellectual functioning" was not available until October 1997), a code of MR may have been used as a "closely analogous" impairment. In other cases, a code of MR may have been used in error even when a valid code for the specific impairment was available. Thus, SSA suspected that many of the children whose eligibility was ceased following a redetermination did not have MR even though the code placed them in that category. To implement the review, MR cessation cases that involved an IQ less than 75 would automatically be reopened; cases where IQ was above 75 would first be reviewed and then reopened if deficiencies were found. This was estimated to affect 40,000 cases. Subsequent SSA internal reports show that 14,146 cessations following redetermination were selected for re-review as the remaining affected cases were already under appeal.<sup>13</sup> In addition, 21,681 denials of initial applications following the implementation of welfare reform with a code of MR were selected for re-review.

**Review of "Failure to Cooperate" Cases.** All redetermination cases where benefits were ceased based on a "failure to cooperate" were to be reviewed to ensure that the cooperation of child beneficiaries' families was fully sought and documented. These cases occurred when the child's parent or legal guardian did not respond to the initial redetermination notice or failed to cooperate with SSA's redetermination process. Cessations based on failure to cooperate made up less than 5 percent of all cases, ranging

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<sup>13</sup>The figure and others that follow in the text are based on the SSA document titled "SSI Welfare Reform Childhood Status Report through October 31, 1998."

from less than 1 percent to 9.5 percent of cases across states. Subsequent SSA internal reports show that 2,577 failure to cooperate cases were selected for re-review.

**Quality Review Provisions.** All Disability Determination Service (DDS) offices were to undertake a review of a portion of their redetermination cessations, beyond those described above. SSA would determine the types of cases to be reviewed by each office, selecting cases with the highest likelihood of error based on quality assurance data.

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